Older adult mistreatment, dementia, and the family caregiver in the Northeastern Ontario home: The influence of context on professional agency

by

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Abstract

This integrated-article thesis presents the findings of a qualitative critical inquiry with three related aims: to understand the experience of formal care practitioners who encounter mistreatment of an older adult with dementia by their family caregiver in the home; to explain the influences of the domestic, health care, geographical, and socio-political contexts upon that experience; and to facilitate empowerment and collective action to improve policy, practice and care outcomes. Viewing this experience through a Critical Social Theory lens, data collection methods consisted of interviews, reflective journals, and inquiry and action focus groups. Practitioners representing 23 organizations providing care to older adults in their homes in urban and rural Northeastern Ontario participated over the course of two phases of Understanding and Empowerment. In this thesis, Chapter 1 will review the literature, identifying gaps in knowledge and describing the critical theoretical underpinnings, methodology and theoretical thematic analysis which were instrumental to facilitate self-reflection of past cases, critique of socially dominant ideologies and structures, dialogue with other practitioners also encountering these cases, and dialectic reasoning, a process of examining contradictions of what is, versus what should be in cases of older adult mistreatment and dementia. Chapter 2 presents the findings on the experience of practitioners with these cases. More specifically, practitioners described a lack of professional agency defined as the ability to control outcomes and act in a meaningful way in their cases. Next, Chapter 3 examines the home, familial, health care, geographical and socio-political contexts and their influences on professional agency. Those findings describe the oppression of these contexts on practitioners who could not control the outcomes of older adult mistreatment [OAM] within them. Chapter 4 then presents the process of empowerment during which practitioners shared their concerns related to these oppressive contexts and collaborated

towards collective action projects to improve policy, practice and outcomes. Chapter 5 situates the significance of the findings within the field of OAM and dementia and discusses cross-cutting themes linking the papers. Limitations of the study will be reviewed as well as recommendations for policy, practice and research.

Keywords: older adult mistreatment, elder abuse, dementia, caregiver, home care, professional agency, rural, urban, northern

Statement of Co-Authorship

The three following papers appearing in this thesis have resulted from this research:

Lindenbach, J., Larocque, S., Morgan, D., & Jacklin, K. Mistreated older adults with dementia in the home: Practitioner experience and unattainable professional agency. Submitted to the *Journal of Elder Abuse and Neglect.*

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Lindenbach, J., Larocque, S., Morgan, D., & Jacklin, K. Practitioner empowerment, older adult mistreatment and dementia. Submitted to *Canadian Journal on Aging.*

The three papers have been written by the student with insightful feedback, revisions, and guidance offered by the members of the supervisory committee Dr. S. Larocque, and Dr. D. Morgan, and director Dr. K. Jacklin. All are therefore co-authors for each paper.

I am aware of Laurentian University's Policy on Authorship and I certify that I have properly acknowledged the contribution of other researchers to my thesis. I have obtained written permission from each of the co-authors to include the above materials in my thesis.

I certify that this thesis, and the research to which it refers, is the product of my own work.

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Chapter 1: Introduction

The field of older adult mistreatment must be concerned with risks: the risks associated with an aging population and rising prevalence of dementia, the increasing demands on family caregivers with systemic failings of health and social services to support the needs of older adults, and the risks that remain hidden within specific contexts such as the home. Policy reform must then respond to these risks, by first acknowledging them and then developing a strong policy or legislative approach to support all involved. In the province of Ontario, Canada, where this study took place, policy is failing to address the numerous risks present when an older adult with dementia is mistreated within their home by their family caregiver. Without specific legislation and infrastructure in the province of Ontario to assign responsibility for these cases to a profession or organization, all formal care practitioners who may have access to this dyad, including health and social care providers, community services, as well as police officers who may be asked to intervene, play crucial roles in the discovery and management of older adult mistreatment. Therefore, this study had three aims: firstly to understand the experience of practitioners who support older adults with dementia and their caregivers within the home where mistreatment is occurring; secondly to expose the contextual influences of current home health care and social services, rural, urban and northern geography, as well as the absence of provincial adult protective legislation and infrastructure; and thirdly, to pursue empowerment of these practitioners towards actions to improve practice, policy, and outcomes for the mistreated older adults with dementia in their care.

Background

Older Adult Mistreatment

Originally labelled “granny battering” (Burston, 1975), and commonly referred to as elder abuse, our understanding of older adult mistreatment [OAM] has progressed due to international research efforts. Despite these advancements, consensus has not been reached on an

acceptable definition of OAM that should ideally offer conceptual clarification, operational measurement, and policy guidance. For this study, OAM is defined as "actions and/or behaviours, or lack (thereof), that cause harm or risk of harm within a trusting relationship" (McDonald, 2015, p. 6). Given the focus on "within a trusting relationship", this definition does not include financial mistreatment perpetrated by strangers, commonly known as scams, nor does it include self-neglect, or Diogenes syndrome, where there is no perpetrator. This definition was chosen as it most closely represents the mistreatment that occurs between an older adult and their family caregiver in the home setting with whom there is a trusting relationship, and where there is a societal expectation of trust, but where this trust could result in abuses of power and control.

Internationally, prevalence rates of OAM vary tremendously due to methodological differences in definitions, challenges inherent to studying this sensitive topic, age of inclusion, and measurement tools. In a review of 20 national-scope international studies that provided aggregate rates (including forms of abuse and neglect), McDonald (2015) concluded that international OAM rates varied from 0.8% in Spain to 36.2% in China.

In Canada, there are three sources of data on OAM. Firstly, Statistics Canada provides an annual report entitled the Family Violence Profile (Statistics Canada, 2013, 2014, 2015, 2016, 2017). Produced by the Canadian Centre for Justice Statistics, it analyses data on police-reported family violence against adults over the age of 65. Data from the last five years (2013-2017) reveals some constants: rates of violent crimes against older adults are rising (56.8; 59.6; 60; 62; 65 victims per 100,000); one-third of older adults are victimized by a family member such as a child, spouse, sibling or other family member; most had physical force used against them, with less use of weapons than other age groups; and violence was consistently higher in rural areas than in urban areas. While helpful to understand violent offences against older adults by a family member, these reports only included offences which fall under the *Criminal Code of Canada* (Government of Canada, 2018), exclude non-violent crimes such as theft and fraud, mistreatment

unsubstantiated by police, homicides unsolved by police and other forms of mistreatment not covered under the *Criminal Code* (Statistics Canada, 2015).

The next source of data is the General Social Survey (GSS) on Canadians' Safety (Victimization) (Statistics Canada, 2015). While it provides information on experiences of victimization, either reported to the police or not, it is a self-reported survey and most probably does not reflect OAM of older adults with dementia.

The final pieces of data are prevalence studies. In Canada, three national studies, of the general older adult population living in the community, have reported prevalence rates of 4% (Podnieks, Pillemer, Nicholson, Shillington & Frizzel, 1990), 4.5% (Lai, 2011), and 8.2% (McDonald, 2015). Although these studies offer the best prevalence information available, as most prevalence studies, participants with cognitive deficits were excluded. As well, the design of random telephone interviews utilized only permits access to a sub-group of older adults (Canadian Centre for Elder Law [CCEL], 2011a). Thus, in Canada, the true prevalence of OAM, for all older adults including those with dementia, remains unknown.

Dementia

Dementia refers to "a large class of disorders characterized by the progressive deterioration of thinking ability and memory as the brain becomes damaged" (Alzheimer Society of Canada, 2010a, p. 10). Studies with this specific population have discovered alarmingly higher prevalence rates of mistreatment: 34.9% (Sasaki et al., 2007); 47.3% (Wiglesworth et al., 2010); 52% (Cooney, Howard, & Lawlor, 2006); and 62.3% (Yan & Kwok, 2011). With these older adults, the OAM may remain a "hidden offence" (Selwood, Cooper, & Livingston, 2007, p. 109) due to specific risks including impaired expressive language and memory loss of events preventing an older adult from revealing the mistreatment and lack of decision capacity to address the OAM (Baldwin, 2009; Hansberry, Chen, & Gorbien, 2005; Cooper, Selwood, Blanchard, & Livingston, 2010). One study has pinpointed new onset or worsening cognitive

impairment as a risk factor for OAM, supposing that time facilitated caregiver adaptation to the impairment (Lachs, Williams, O'Brien, Hurst, & Horwitz, 1997). In a study by Coyne, Reichman, & Berbig (1993), mistreating caregivers had been providing care for longer, were caring for older adults with a lower functional level, and scored higher on burden and depression scores. Characteristics of maladaptation, caregiver anxiety, caregiver burden and depression have also been identified (Buckwalter, Campbell, Gerdner, & Garand, 1996; Cooper et al., 2010; Dyer, Pavlik, Murphy, & Hyman, 2000; Paveza et al., 1992).

When considering interactions within the dyad, responsive behaviours of dementia (Cooney et al., 2006; Cooper et al., 2010; Coyne et al., 1993; Lachs et al., 1997: Lachs & Pillemer, 2004; Paveza et al., 1992) appear to create a "dyadic vulnerability" (Fulmer et al., 2005, p. 525; VandeWeerd, Paveza, Walsh, & Corvin, 2013). These behaviors, not usually present in the early or late stages of dementia, typically increase in the middle stage of the illness (Alzheimer Society of Canada, 2010b, p. 8). Therefore, risks may vary as the illness progresses. Although a frequently cited study by Gainey & Payne (2006) refuted caregiver burden as a risk factor for mistreatment of older adults, their study only considered the documented diagnosis of a dementia, not the stages described above. Personality changes (Cooper et al., 2010) and loss of the older adult's "personhood" (Feast et al., 2016) have been described as contributors to OAM. Feast and colleagues explain that responsive behaviors are perceived by family as evidence that the person has lost, or is losing their identity to the disease, a perception which is devastating to families. By losing one's identity, one's worth is subsequently reduced, perhaps contributing to the risk of OAM (Boddington & Featherstone, 2018).

In addition to concluding that this group is at higher risk for mistreatment, these rates are considered underestimations as more serious forms of mistreatment may not be reported by caregivers and those most at-risk are probably not reached (Cooney & Howard, 1995; Cooney et al., 2006; Paveza et al., 1992; Wiglesworth et al., 2010). This is therefore a particularly at-risk

group of older adults, and in Canada, where the prevalence of dementia is projected to rise several-fold (Alzheimer Society of Canada, 2010a), research with those practitioners who accompany these dyads is imperative.

Family Caregiver

This study specifically focused on OAM cases perpetrated by a family member, an "overlooked" component of family violence (Lowenstein, 2010, p. 216). This decision was based on the pivotal relationship in home care where responsibility for care or protection has been assumed by the family caregiver or there is an expectation of such trust from a legal or social standpoint (National Research Council [NRC], 2003). Despite these expectations, research has repeatedly demonstrated that older adults are more frequently victimized by their adult children or spouses, with rates as high as 85-90% (Amstadter et al., 2011; Choi & Mayer, 2000; Friedman, Avila, Tanouye, & Joseph, 2011; National Center on Elder Abuse, 1998; NRC, 2003; Weeks, Richards, Nilsson, Kozma, & Bryanton, 2005). A recent Statistics Canada analysis (December 2018) concluded that: 1) between 2009 and 2017, the rates of family violence against older adults increased 6%; and 2) "frustration, anger or despair (36%)-a range of emotions typical of offenders exerting control over victims-and argument or quarrel (34%) were the most common primary motives for family-related homicides of seniors between 2007 and 2017" (p.2).

Caregiving Responsibility: Provincial Home Care, Family and Society

In Canada, while the health care system, referred to as Medicare, is federally funded, each of the 13 provinces and territories is then responsible for the administration of their own health insurance plan (Government of Canada, 2016). Home care services, although not considered medically necessary services under the Canada Health Act, are funded and managed by individual provincial governments (Ontario Ministry of Health and Long-Term Care, 2012). Fiscal constraints, strict eligibility criteria, and limited service allotments characterize this home care system (Yakerson, 2019).

Within this province, perception is that long-term supportive care, such as caregiving for a loved one with dementia, is a family responsibility versus that of the provincial home care institution (Hollander, Chappell, Prince, & Shapiro, 2007). Such societal ideologies of family caregiving are also dominant elsewhere influencing not only expectations but also intervention and resources (Anetzberger, 2000; Lowenstein, 2010). In regard to OAM, when asked, 94% of Canadians thought that family played the most important role in protecting older adults (Human Resources and Social Development Canada, 2008). These expectations may result in not expecting OAM or a reluctance to pursue it when occurring within the sanctity of the family. For example, in rural China, Wu and colleagues (2012) reported an elevated prevalence rate of 36.2%. The authors concluded that despite strong traditional beliefs of filial piety, these values are "breaking down" (p. 2) and OAM remains hidden as it is considered a family affair in which outsiders should not interfere. Canadian researchers Brozowski & Hall (2004) have also expressed concern that the changing notion of family is leading to intimate relationship instability, a factor which will contribute to increased risk of OAM in our society.

Given the importance of the institution of family, the domestic setting often remains unseen and OAM remains relegated to a family problem rather than a societal one (Brandl & Raymond, 2012). When the mistreatment remains hidden from society, it is allowed to escalate in severity (World Health Organization/ International Network for the Prevention of Elder Abuse [WHO/INPEA], 2002). In Canada, 92.1% of older adults live in private dwellings versus in institutions (Statistics Canada, July 2018). With the ongoing shift towards aging at home in Ontario, increased responsibilities of the family caregiver, the knowledge that most mistreatment is actually perpetrated by a family caregiver and the increased rate of family violence against older adults (NRC, 2003; Statistics Canada, December 2018; Statistics Canada, July 2018), exploring the home care context is imperative.

Rural Context

This study took place in the Northeastern region of Ontario, a province within Canada (Appendix A). This region, which covers 400,000 square kilometres, represents 44% of Ontario's land mass yet is home to only 4% of the province's population (North East Local Health Integration Network [NE LHIN], 2014). Within this region, where the proportion of older adults is projected to increase from 20% to 27% by 2026, and where some remote parts are only accessible by air or ice roads, Ontarians have a markedly lower life expectancy, substantially higher rates of some chronic diseases (ie: circulatory and respiratory diseases), and are much less likely to be able to access a health care practitioner than in Ontario overall (Health Quality Ontario, 2017). Given this large geographical dispersion, the wish to conduct data collection in-person, and winter driving conditions, the primary researcher targeted five geographical areas, visiting eleven urban, rural, and northern communities while participants from three more northern or remote communities participated by teleconferencing.

For this study, rurality was defined using the Rural Small-Town definition: "towns or municipalities outside the commuting zone of larger urban centres (with 10,000 or more population)" (du Plessis, Beshiri, Bollman, & Clemenson, 2001). Applying this definition to data from the 2011 Canadian Census, regions were classified as either rural or urban. Next, although all areas of Northeastern Ontario are considered "northern" (Health Quality Ontario, 2017), with harsh winters lasting approximately six months in this area, for the purpose of this study, regions were only considered "northern" if winter closures of Trans-Canadian highways prevented access to these communities. Practitioners stressed the importance of this factor in their ability to care for the older adults/caregivers in their care.

Within the NE LHIN, there are both urban and rural regions. Both were included so as to gain an understanding of geographical contextual influences on the experience of professional agency with these cases that were similar or unique to these regions. The scientific literature does

address rural challenges such as early placement on long-term care waiting lists due to lack of resources in rural communities (Kuluski, Williams, Berta, & Laporte, 2012); insufficient home care in many rural communities (Canadian Home Care Association, [CHCA], 2006); out-migration of young individuals, a lack of support systems and local resources, limited transportation, and the requirements to travel long distances and hours for services (CHCA, 2006). Inequities in regards to access to services and options for older adults at risk or experiencing OAM in rural and northern communities have been shared by stakeholders during ministerial round tables on elder abuse with Minister of State for Seniors (Human Resources and Skills Development Canada [HRSDC], April 26, 2012). For example, the National Initiative for the Care of the Elderly [NICE] Elder Abuse Team: Knowledge to Action project, was concentrated in 5 large urban centers throughout Canada (NICE, 2012). Rural communities had little knowledge of this project and the helpful tools it created. Therefore, this study sought to understand any such differences or similarities influencing practitioner experience.

Internationally, researchers have studied OAM within the rural context. Although not an exhaustive list, these have occurred in Australia (Cupitt, 1997), the United Kingdom (Cornes, Manthorpe, & Haselden, 2010), Spain (Garre-Olmo et al., 2009), China (Wu et al., 2012) and the United States (Amstader et al., 2011; Blundo & Bullington, 2007; Buckwalter et al., 1996; Dimah & Dimah, 2003; Fitzsimons, Hagemeister, & Braun, 2011; Vandsburger, Curtis, & Imbody, 2012). Numerous factors appear to increase risk of mistreatment with rural older adult/caregiver dyads including: physical and social isolation; determinants of health such as lack of employment leading to financial dependence on the older adult; aging demographics; centralisation and rationalisation of services such as police and clergy; a lack of fundamental home care and the inability to provide a safety net; the reluctance of some rural older adults to accept formal health services; and the outmigration of caregivers which cripples the informal support system (Amstadter et al., 2011; Blundo & Bullington, 2007; Brozowski & Hall, 2004;

Cupitt, 1997; Dimah & Dimah, 2003; Fitzsimons et al., 2011; Garre-Olmo et al., 2009; Harbison, Coughlan, Karabanow and VanderPlaat, 2005; MacKay-Barr & Csiernik, 2012; Statistics Canada, December 2018; Vandsburger et al., 2012). However, as most studies are conducted in urban centers, understanding the impact of contextual rural risk factors on professional practice and care outcomes in these rural cases is greatly reduced (Amstadter et al., 2011; Buckwalter et al., 1996; Cornes et al., 2010; Harbison et al., 2005).

Canadian mistreated older adults have been depicted as having 'psychological hardiness' (Harbison et al., 2005; Podnieks, 1993). This belief, and the opposite findings of the isolation inherent to the rural context, combine to create OAM opportunities (Spencer, 2000), to make it difficult for older adults to accept assistance, and for practitioners who feel like outsiders to offer assistance (Harbison et al., 2005). While family violence might not be expected to occur in the rural context (Dimah & Dimah, 2003), it is precisely the ideal vision of small-community living that contributes to a lack of awareness of community problems and creates a cloud of secrecy over the mistreatment (Fitzsimons et al., 2011). In Canada, few studies on OAM within the rural context have been conducted (Harbison et al., 2005; MacKay-Barr & Csiernik, 2012; Stones & Bédard, 2002; Weeks et al., 2005). Due to this scarcity, each Canadian study merits description. Two of these studies were conducted within provinces with adult protective legislation and, although noted to provide some contextual understanding, a thorough description of the legislative Canadian landscape will be offered in the next section.

Harbison and colleagues (2005), in rural Nova Scotia, one of the Canadian provinces with adult protective legislation, interviewed practitioners of various disciplines obliged to report suspected mistreatment to adult protection workers. The aim of this exploratory study was to understand how practitioner interventions were congruent with what mistreated rural older adults wanted. Practitioners described the importance of having these adult protection workers, even for consultation when not directly involved in the case. These workers were part of the

interdisciplinary team, were trusted, assisted with brainstorming, and with crisis management serving as a "sounding board" (p. 239). The study focused on traditionally accepted rural values and the ethics of reporting OAM as per adult protective legislation which does not exist in the province focused in this study. The complexity of high-risk cases of OAM and dementia are not addressed nor is the experience of these practitioners.

In Chatham Kent, a rural region of south western Ontario, MacKay-Barr & Csiernik (2012) employed older adults to interview 236 of their healthy peers residing in all settings with the exception of long-term care. The aim of their study was to describe the knowledge of OAM held by healthy older adults as well as the self-disclosed prevalence of OAM. Of this healthy subgroup, nearly 1 in 5 (19.1%) disclosed that they had suffered mistreatment, a rate more than double the latest prevalence finding of 8.2% (McDonald, 2015). These authors concluded that a different subgroup of unhealthy, frail and isolated older adults would be at increased risk of mistreatment.

Stones and Bédard's (2002) Canadian survey of 339 older adults and 233 practitioners asked them to rate 112 items covering a wide range of mistreatment severity. Higher ratings were given by practitioners rather than seniors and by residents in smaller (rural) rather than larger (urban) communities. Therefore, rural older adults and practitioners held higher thresholds for what was considered mistreatment. Rural practitioners dealing with these cases have reported frustration with rural older adults who appear to be conditioned to this lifestyle, having normalized the mistreatment to protect their family (Fitzsimons et al., 2011; Vandsburger et al., 2012). These beliefs may lead to lack of disclosure (Amstadter et al., 2011) for fear of reprisal or loss of the caregiver's assistance (Cornes et al., 2010; MacKay-Barr & Csiernik, 2012).

Lastly, in Prince Edward Island, a province that has adult protective legislation, Weeks and colleagues (2005) surveyed 121 practitioners who had contact with mistreated older adults to explore characteristics of the older adult, perpetrator and family context that increased

mistreatment risk. Older adults with dementia were more at-risk for mistreatment, 70% of abusers were family members, and isolation of the dyad was related to power and control.

Within the literature, a prevailing ideology is that rural informal networks, such as friends and neighbours, can adapt to and compensate for the lack of formal services (Harbison et al., 2005). In the United Kingdom, Cornes and colleagues (2010) reported that while some rural informal networks played an important "role in safeguarding" (p. 23), this was less possible in more remote and isolated settings. As well, the informal support network of extended family is being eroded due to the outmigration of younger generations (Wu et al., 2012) and to the failing health of aging neighbours (Dimah & Dimah, 2003; Fitzsimons et al., 2011). Despite the belief that family networks are strong in rural communities, others have proposed that the rural isolation can keep "victims hidden away from outside scrutiny" (Cupitt, 1997, p. 23). Furthermore, one researcher commented that further research was required to discover why "rural populations, who by all accounts have strong family networks, turn on their aging relatives" (Dimah & Dimah, 2003, p. 90).

OAM Legislation

Next, the influence of the legal context on this experience has not been addressed in areas where there is no legislation and infrastructure specific to older adult protection. In Canada, where there are ten provinces and three territories, jurisdictions all differ in their legislative approach to OAM leading to much variation and inconsistency across the country. The Canadian Centre for Elder Law [CCEL] (2011a), in a review of these jurisdictional differences, has provided five categories of legal frameworks. To begin, the provinces of Ontario, Alberta and Manitoba have a "Residential Care Regime", meaning that while there is no general adult protection legislation, some specific legislation is in place for adults residing in or receiving services, from certain care facilities such as nursing homes. The second category, named "Comprehensive Adult Protection Regimes", exists in British Columbia, Yukon, New

Brunswick, and Prince Edward Island. Here, a specific law addresses mistreatment broadly, including all adults (with disabilities, domestic violence, and older adults) and in all contexts (care facilities and home). As well, this type of regime provides, in addition to reporting duties, many potential responses to mistreatment such as powers of access, to investigate allegations, and sharing of confidential information for the purpose of an investigation. The third category, named a "Protectionist Regime", exists in Nova Scotia only. In this province, the general population has a duty to report any mistreatment, regardless of contexts, with failure to report an offence. The fourth category, in Saskatchewan, Quebec, Nunavut, and the Northwest Territories, is referred to as a "Patchwork Regime". Here, family violence legislation, a restricted focus on financial mistreatment, or a human rights approach is primarily used as opposed to adult protection. The final regime, of "Neglect Legislation", exists in Newfoundland. Here, abuse is not addressed as their Act only addresses the neglect of older adults. (As a Canadian legislative review is beyond the scope of this thesis, readers are encouraged to consult reviews by Hall (2009), the Department of Justice Canada (2015), and the CCEL, 2011a, b).

In summary, five jurisdictions have developed adult protection and guardianship legislation (Department of Justice Canada, 2015), but in Ontario, there is neither such legislation nor infrastructure.Within Ontario, protective legislation currently only exists for victims of intimate partner violence, at-risk adults with developmental disabilities (since birth), older adults in long-term and residential care institutions, and for children (*Domestic Violence Protection Act, 2000; Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008; Long-Term Care Homes Act, 2007; Retirement Homes Act, 2010; Child, Youth and Family Services Act, 2017)* (Government of Ontario, 2018a, 2018b, 2018c, 2018d; 2019a). In some documents, a reference is made to the possible professional and ethical obligation of health care professionals to report mistreatment under the *Regulated Professions*

Act, 1991 (Government of Ontario, 2019b). However, this only applies to the mandatory reporting of sexual misconduct by another health care professional under section 85.1.

Without specific adult protective legislation in this province, the *Criminal Code of Canada*, *1985*, while it does not specifically address OAM, is to be used when OAM in the home is considered a criminal offence (Government of Canada, 2018; Law Commission of Ontario [LCO], 2012). However, for numerous reasons, the Code is seldom applied to address OAM: reluctance to reveal the mistreatment to authorities, delays in the system where victims may die or be incapable by trial time (LCO, 2012; Podnieks, 2008); and abuse of power of attorneys where there is no mechanism to ensure they are used correctly (HRSDC, 2012). In addition, by the time mistreatment is recognized under the Code which in referring to neglect uses language such as "endangering the life" and "permanent injury", cases usually present "appalling circumstances" (CCEL, 2011a, p. 23). Finally, even if the mistreatment is a criminal offence, there is currently no law in Ontario enforcing the mandatory reporting of mistreatment occurring in the home context (Solomon, 2009; Wahl, 2013). Therefore, in Ontario, a practitioner who encounters OAM within the home context has no legal obligation to report the incident to the authorities. Furthermore, in Ontario, consent is required to disclose OAM, except in cases of significant risk of serious bodily harm, to prevent an act of violence, suicide, imminent danger or when assisting with a police investigation (CCEL, 2011b).

For many years, the United States led the way in adult protection, with all states having some form of legislation (Bergeron, 1999; Dong, 2012; Killick & Taylor, 2009; Mixson, 2010). However, progress is also now occurring in the United Kingdom with promising developments in policy reform and adult protective legislation development. The nations of England, Scotland, and Wales have placed adult protection on a "statutory footing", while the nation of Northern Ireland has adopted numerous policy reforms in this regard (Montgomery et al., 2016). Although more studies are needed to evaluate these new measures on OAM case outcomes, findings of

those conducted thus far are favourable. Researchers have discovered greater cost-effectiveness and higher substantiation rates of certain models (Stevens et al., 2017); greater interprofessional collaboration (Mackay & Notman, 2017); clearer roles and responsibilities (Montgomery & McKee, 2017); as well as practitioner empowerment (Mackay et al., 2011; Mackay et al., 2012). Until such progress can occur in Ontario, practitioners, without adult protective legislation, must understand a piecemeal of laws related to context, capacity, and privacy (Solomon, 2009; Wahl, 2013).

Practitioner Experience

The professional experience of encountering OAM in the home has been eloquently described by Anetzberger (2005) as an assault on the senses; the sense of sight is challenged by bruises or burns; the sense of smell is overwhelmed with odours of urine-soaked mattresses; the sense of hearing can be shocked with psychological mistreatment that can leave the practitioner in a state of fear or anger. When facing what seems to be an intolerable situation, practitioners may not have the awareness that they can act (Fulton, 1997).

Earlier studies with adult protective workers have revealed challenges in these cases (Mixson, 1995; Dong, 2012; Killick & Taylor, 2009). When facing equally unsatisfactory options and an inability to resolve cases, avoidance and countertransference of professional helplessness onto the mistreated older adult were described (Bergeron, 1999; Wilson, 2002). In Canada, where the majority of provinces do not have adult protective services, very few studies have explored this experience.

Only a handful of studies have been conducted in socio-legal contexts similar to Ontario: in Japan (Omote, Saeki, & Sakai, 2007), Sweden (Erlingsson, Carlson, & Saveman, 2006; Erlingsson, Ono, Sasaki, & Saveman, 2012; Saveman, Hallberg, & Norberg, 1993), and in Quebec (Beaulieu & Leclerc, 2006; Lithwick, Beaulieu, Gravel & Straka, 1999). These studies

greatly assist in exposing the challenge of this encounter within the home without supportive legislation.

For example, in the home care context of Japan, a study by Omote and colleagues (2007) interviewed 21 care managers obtained by purposive and snowball sampling. When asked to describe cases they encountered in the home setting, fear and constant worry were shared by care managers due to the "tacit control" exerted by the abusive caregiver (p.569). In most cases, the presence of the abusive caregiver was unavoidable and care managers feared an increase in mistreatment if the caregiver was provoked. Guided by their perceived responsibility to protect them, these care managers reported feeling alone, powerless and trapped. In many cases, a service plan was agreed upon but shortly thereafter the caregiver restricted access to the older adult. Strong beliefs of family sanctity also influenced interventions as some care managers admitted to ignoring the mistreatment because it occurred within the home. In other cases, when mistreatment was not witnessed during their visits, some care managers, admitting self-doubt in their ability to intervene, resorted to denial and rationalisation of the caregiver's burden. In many cases, the professional's inability to "act on their resolve to do something about the situation" eventually lead to the "abandonment" of the older adult (p.574).

In Sweden, 21 district nurses described OAM cases in which they intervened (Saveman et al., 1993). These nurses described that, in the absence of guidelines, decisions in these complex cases were based on intuition and attempts to understand the experience of the mistreated older adult and the intent of the caregiver. Erlingsson and colleagues (2006), also in Sweden, conducted focus group interviews with 31 participants obtained through convenience and purposeful sampling. These participants described denial when encountering mistreatment, frustration with unclear and inefficient procedures, a tolerance for mistreatment and a tendency to blame the older adult victim.

In Quebec, Beaulieu and Leclerc (2006) revealed practitioner stress, powerlessness and disappointment when intervening in cases of OAM. Using snowball sampling, sixteen psychosocial practitioners were asked, "How far should we go" in reference to cases encountered in their practice. In attempting to cope with this experience, limited by lack of time, insufficient resources, loss of patient autonomy, the dangerousness of the situation, and collaboration with the older adult/caregiver dyad, practitioners intervened along a practice continuum. The continuum ranged from negative autonomy that was deemed to result in "patient abandonment" (p. 171); here practice included closing cases without active intervention, the denial of the need for intervention or the passing of responsibility onto others. Especially in cases of doubtful older adult cognitive autonomy, psychosocial practitioners reported uncertainty and powerlessness, which resulted in "relinquishment, withdrawal and denial" (p. 177). In the middle ground, during accompaniment, psychosocial practitioners described the stress of having to tolerate certain risks and the overwhelming accountability related to these litigious situations. At the other end of the spectrum, when practitioners were forced to proceed with extreme measures of protection without accounting for the older adult's autonomy, some felt distressed after the occurrence. Others reported an extreme scrutiny by colleagues to resolve the mistreatment along with perceived similar societal expectations. Worry, fear, being conscious of the danger for the older adult, and feelings of incompetence with at-risk victims of mistreatment resulted. Protection of at-risk older adults by practitioners was considered the minimal societal expectation and practitioners reported the pressure of this accountability. This study, although greatly contributing to knowledge of professional ethics within a similar socio-political context without adult protective legislation, differs in many ways from my proposed study: it was limited to psychosocial practitioners (believed to be social workers), included cases of cognitively well older adults, did not focus on the context within which decisions were made, and did not address mistreating characteristics of the dyad. Nevertheless, this study provided practitioners with an

opportunity to be heard and greatly contributes to our understanding of the complexity of this professional experience.

Lithwick and colleagues (1999), also from Quebec, analysed 128 OAM cases from community agency files. Professional assessment was challenged by older adult cognitive deficits and interventions were aimed at harm reduction versus the elimination of mistreatment, the latter considered an impossible goal.

Professional Agency

Given the challenges described by practitioners, a specific component of this experience became a focus for this study: that of professional agency. The concept of agency has been defined differently in the literature, either having an individual focus or a contextual embeddedness. For this study, to address the complexity of the practitioner's experience with OAM, dementia, and caregiving, the definition of agency by Frie (2011) was most appropriate. Basing his conceptualization on social theory and philosophical hermeneutics, Frie (2011) defined agency as: "an emergent, affective, and cognitive process that permits us to respond to our situations in meaningful ways…it points to the ethical and political implications of human action" (p. 341). It also speaks to the serious and sometimes fatal outcomes of decisions taken in these cases, the ethical dilemmas faced, and the influence of context on decision-making as Frie (2011) explains that agency "…exists within broader sociocultural contexts…situated agents can reason and act only as a result of the … contexts in which they are embedded…without a coherent notion of agency, our ability to confront political and ethical challenges is severely limited" (p. 347). This description situates practitioners within a larger context as recognized by some prior studies on OAM (Killick & Taylor, 2009; Norris, Fancey, Power, & Ross, 2013). Lastly, Frie's definition addresses the need to hear the voices of those impacted by the experience: "when persons have no voices other than prevailing discourses in which they exist, not only is agency dismantled, the possibility of social, political, and psychological change is

undermined" (p. 348). To the knowledge of the primary researcher, no study has explored the concept of professional agency when older adults with dementia are mistreated within their homes.

The Critical social theory [CST] (Habermas, 1971, 1976, 1984) lens chosen to frame this study has led me to consider that a lack of professional agency is reflected in the handful of studies that have explored decision-making in cases of OAM. Although practitioners describe feeling powerless in OAM cases (Beaulieu & Leclerc, 2006; Omote et al., 2007), the reasons underlying their decision-making and actions remain unknown. CST, which posits that an experience can only be understood by exploring its contextual influences (Maggs-Rapport, 2001), will therefore be able to guide the discovery of these root causes (Grant & Giddings, 2002).

Given the aging demographics in Northeastern Ontario, the projected Canadian rise of dementia prevalence, the alarmingly high prevalence rates of mistreatment of older adults with dementia, the shift from institutional care to home health by family caregivers who are most often the perpetrators of OAM, it was imperative that professional agency in cases of mistreatment of an older adult with dementia within the rural and urban home setting be explored. Furthermore, the socio-legal context of OAM in Ontario places the sole responsibility of care in these cases upon the practitioners involved in the case, and this despite the lack of legislation and infrastructure. Due to the complexity of cases, the importance of professional agency to intervene, and the gravity of potential consequences for the older adult, caregiver, and practitioner, understanding this experience and its contextual influences will pave the way towards action to improve practice, policy, and outcomes for mistreated older adults.

Study Purpose

This study therefore aimed to understand the experience of practitioners, situated within a context, and ultimately to empower those involved to improve their practice, contribute towards

policy change, and improve outcomes for mistreated older adults with dementia. This two-phase study, of Understanding and Empowerment, aimed to answer the following main research question: In cases of mistreatment of older adults with dementia by caregivers, how does the rural and urban socio-legal home health context influence the professional's ability to exert agency? To narrow this focus, sub-questions guided each phase of the study.

In the first phase of Understanding, individual in-depth interviews, reflective journals and inquiry focus groups aimed to answer the following:

a) Within the contexts of rural and urban Northeast Ontario, when older adults with dementia are mistreated by their family caregivers, how do practitioners experience agency?
b) When reflecting on past cases of mistreatment of older adults with dementia by a caregiver, what are practitioners' underlying beliefs, understandings, and motives?
c) How do prevailing ideologies and dominant structures influence professional agency?
d) Within the contexts of rural and urban Northeast Ontario, do practitioners perceive a need to improve their agency when older adults with dementia are mistreated by their family caregivers?

In the second phase of Empowerment, Action focus groups aimed to answer the following:

e) Within the context of rural and urban Northeast Ontario, what changes in the socio-legal health care context do practitioners want to act upon to increase professional agency when older adults with dementia are mistreated by their family caregivers?

Methodology

Theoretical Underpinnings

The theoretical framework for this study included the theoretical lens of CST (Habermas, 1971, 1976, 1984), the philosophical roots of Freire (1972), as well as the concept of professional agency of Frie (2011).

Based on historical realism, CST explains that reality is socially and politically constructed (Edgar, 2006; Ruangjiratain & Kendall, 1998). This type of critique must examine the dominant structures and prevailing ideologies which form a virtual reality where values, assumptions, and beliefs are unconsciously adopted, and therefore are not necessarily one's own (Lincoln, Lynham, & Guba, 2011). Dominant social structures determine how power and privilege are assigned in society (Harden, 1996) and subsequently how some groups are oppressed, defined as being kept down by an unjust system (Freire, 1972). Applying this notion to OAM, dominant societal structures that might shape values and beliefs with OAM and dementia cases are assumptions about family constitution and caregiving, dementia care, the health care and social services systems, as well as legislation and law enforcement. Ideologies, which are internalized in these structures, usually remain unquestioned and are embedded in a practitioner's practice (Harden, 1996; Spratt & Houston, 1999). In OAM, one such socially embedded ideology is ageism which can strongly and unconsciously influence OAM and dementia cases. CST therefore framed this critical study so as to expose power and oppression possibly resulting from these structures and ideologies (Boychuk Duchscher, 1999; Freire, 1972; Habermas, 1971, 1976).

To understand phenomena, they must be considered within both their historical and structural context (Fulton, 1997; Harden, 1996). Therefore, CST, which fits within a contextualist paradigm (Maggs-Rapport, 2001), guided the study of participants' meanings of their experience of professional agency and the way broader contexts influence those meanings (Braun & Clarke, 2006).

To assist in the comprehension of the embeddedness of experience, Habermas (1984) proposes the notions of the lifeworld, a symbolic place where human rights and relationships prevail in the experience of everyday life, and the system-world of economy and power that can restrict and dominate everyday life (Edgar, 2006). Donnelly and colleagues (2013) explain that

experiences involving human rights and relationships in the delicate lifeworld are in a dialectical struggle with the confines and power of the system-world. This study therefore sought to understand the contextual influences of the system-world on the professional experience with OAM. According to Hage & Lorensen (2005), these understandings permit one to gain control over one's life, and to actively influence the system-world.

Habermas (1976) differentiates three types of scientific knowledge, each with a corresponding mode of action: cognitive-instrumental knowledge, which leads to a strategic mode of action seeking to control by use of power in an objective world and failing to recognize subjective human activity; aesthetic-expressive knowledge, which leads to an interpretive mode of action where the subjective world can be understood; and a moral-practical knowledge which leads to emancipatory action where social justice prevails, and any oppression by the objective world is challenged (Granero-Molina, Fernandez-Sola, Munoz Terron, & Torres, 2015; Harden, 1996; Hyde et al., 2005; Scheel, Pedersen, & Rosenkrands, 2008). It is the latter, an emancipatory knowledge, that lies the product of CST research (Maggs-Rapport, 2001).

The achievement of emancipatory knowledge is further explained by Habermas in his Theory of Communicative Action (1984). When individuals share their reflections, values, and beliefs within an environment free of oppression, communicative reason versus instrumental reason, leads to collaborative critique, understanding, and validation (Spratt & Houston, 1999). This type of reason therefore results in communicative action, a communal activity where shared goals are identified and the "rational resolution of problems over truth and moral goodness" occurs (Edgar, 2006, p. 23).

Developing critical knowledge is therefore the path to emancipation. CST facilitates reflective consciousness of one's current beliefs and values that have developed due to historical hidden societal power imbalances, interpretive understanding, and action (Comstock, 1982; Jacobs, 2014; Ruangjiratain & Kendall, 1998; Sumner, 2010; Weaver & Olson, 2006). Within

CST research, the researcher role is one of activist and "transformative intellectual" (Lincoln et al., 2011, p. 110) in order to raise the participants' consciousness of oppressive social structures and ideologies as the catalyst to collective action (Grant & Giddings, 2002).

Freire (1972) proposed that to achieve emancipation, awakening of one's critical consciousness about one's experience and how it is influenced by dominant structures and ideologies, is required (Boychuk Duchscher, 1999; Mooney & Nolan, 2006). Being critically conscious must then be followed by social action, as it otherwise remains "wishful thinking" and powerlessness remains (Harden, 1996, p. 36). Emancipation therefore relies on the process of praxis, whereby experiences are critically reflected upon, shared with others through dialogue, and collective action is untaken (Fontana, 2004; Halman, Baker, & Ng, 2017). Emancipation, which seeks reason and the capacity to be "self-reflective and self-determining" (Kendall, 1992, p. 6) is also congruent with Frie's (2011) concept of professional agency which reflects the "human capacity for reflective action and choice" (p. 341). Lastly, the concepts of professional agency, empowerment, and emancipation are all communal activities that require collective action by communities or groups who are encountering the same oppression (Halman et al., 2017).

Self-reflection

To develop an openness to others and self-awareness, critical theory begins with a process of self-reflection (Duffy & Scott, 1998) to assist the researcher in becoming aware of preunderstandings and realize a certain amount of control, although this can never be complete (Nuyen, 1994). Here are excerpts of my journaling prior to designing the study, and throughout data collection and analysis:

As a previous nurse care coordinator, I can attest to the complexity of OAM. Cases of mistreatment by a family caregiver within the home were particularly difficult. Ultimately, the care coordinator carried the responsibility for the case.

One particular case has remained with me. Suspecting neglect of an older adult, I felt helpless presenting the case to my supervisor: the client did not meet eligibility criteria for our services but I felt needed protection from his mistreating caregiver. A minimal service plan was accepted based on my intuition. The mistreating caregiver did not allow any unsupervised exchanges between the client and me. Despite concerns received from front-line practitioners in the home, the caregiver would not permit increases to the service plan. Within a month, I received a chilling unemotional call from this caregiver that the client had died from a fall. Despite my intuition that his death was related to the mistreatment, I had to close the file and carry on with my caseload.

When deciding if this study was needed, and given my absence from case management for 10 years, I consulted with past colleagues still working in the home care sector. They confirmed that these cases remained problematic: documentation continued to be avoided due to feared ramifications, confidentiality and privacy legislation were sometimes not followed, and practitioners simply did not know how to intervene. Now a critical researcher in this field, I was uneasy with a research-policy-practice gap: some academic literature proposes that practitioners lack knowledge or will to intervene, supportive policy is lacking, and practitioners perceive that researchers do not understand front-line reality.

Throughout data collection and analysis, I also came to the realization that I had missed some cases in my own practice, dismissing my intuitive alarm, normalizing the caregiving situation, permitting my own limiting beliefs about dementia to cloud my professional judgement. Yet I was, at the time, a member of our OAM education team, had attended conferences on the matter, on capacity and on dementia and had recognized mistreatment within my caseload. I also experienced nightmares about mistreatment after my 5th interview for which journaling was very helpful. As researching sensitive topics can be distressing, researchers must acknowledge the potential threat of permitting themselves to be reflexive (Probst, 2015).

Although unpleasant, it helped me to achieve greater understanding of my participants' experience.

Design

The study design was based on the theoretical framework described above, Fontana's (2004) principles for critical research, as well as Comstock's (1982) methodology for critical research. Four primary principles inherent to a critical study merit description: reflection, dialogue, critique, and dialectic reasoning (Fontana, 2004).

Firstly, participants benefit from self-reflection that leads to increased self-awareness and liberating change (Duffy & Scott, 1998; Freire, 1972; Fulton, 1997; Habermas, 1984). This self-reflection may occur individually or in group settings where a participatory self-reflection can reveal beliefs, values, and assumptions.

Secondly, dialogue, required for interpretive meaning, is a conversation without power differentials aimed at understanding one's beliefs, values and feelings as well as each other's world (Bennett, Bergin, & Wells, 2016; Boychuk Duchscher, 1999). Scheel and colleagues (2008) refer to dialogue in keeping with accepted ethical norms. During data collection in this study, the goal was therefore to create "communicative spaces" (Bevan, 2013), where participants' voices could be heard, either individually or in a group setting where mutual understanding could result in a "greater richness and depth of narrative" (p. 15).

Next, as phenomena cannot be studied in isolation of their context, external and internal critique occurs throughout the study (Fontana, 2004). Grant & Giddings (2002) explain that the external critique of ideologies and social structures permits a contextual understanding of forces that constrain power while the internal critique serves to discover individual meaning.

Finally, the process of dialectic reasoning presents opposing points or contradictions between subjective and objective realities and confronts them in an attempt to make sense between what is and what should be (Boychuk Duchscher, 1999; Fontana, 2004). Here, Harden

(1996) explains that social values are social facts, they are intertwined, and that it is unwise to try to separate them, as both are required to explain problems confronted by humanity. Spratt & Houston (1999), with practitioners of child protection services, refer to this process as the release of dialectical powers that can serve as the incipient point for change.

Critical research is therefore political in nature, in that change is an objective of the study (Fontana, 2004). The conscientization achieved by understanding oppressive contradictions and conceiving of collaborative actions to become engaged is a product of critical research (Harden, 1996). This study aimed to understand the experience with OAM and dementia, situate it within influencing contexts, and eventually, engage participants in meaningful social action to bring about change. Comstock's (1982) steps for critical research have been integrated throughout this two-phase study.

Source of Participants

In CST research, chosen participants are "social agents (with) progressive tendencies…interests, purposes, or needs that cannot be satisfied within the context of the present social order...that they do not control… (and who) are willing to put the research findings into practice" (Comstock, 1982, p. 379). Participants consisted of formal care practitioners from five organisations providing health and social care as well as community services supporting older adults in their home in both the rural and urban contexts in Northeastern Ontario. Certain characteristics of the chosen participants motivated this decision: access to the home context, high level of responsibility in these cases, potential risks involved, intimate knowledge of the dyad, and possibly close long-standing relationship held with the dyad.

Sampling and Size

After initial communication with management from each organization, a formal information letter was sent to each organization seeking support to invite their employees in the study (Appendix B). All organizations responded favourably to the formal invitation.

Preliminary discussions with the five organizations revealed that management may not have knowledge of past cases of OAM and dementia encountered by their practitioners; the invitation therefore needed to reach all employees. Management disseminated a participant information letter by email describing the aims, phases and significance of the study (Appendix C) with an email invitation (Appendix D). Interested participants were asked to contact the researcher by email. Two organizations limited participation due to human resource challenges. Snowball sampling then followed as potential participants who had information-rich cases were identified (Creswell, 2013). As recommended by Morse (2015), sample size and appropriateness were considered. To develop a complete understanding of the experience of participants in their communities, a sufficient number of interviews and focus groups were required from each geographical region, and from the various types of practitioners involved in these cases. . This would ensure validity as variation and depth of analysis were made possible (Morse, 2015). It also contributed to internal reliability as key issues resembled each other in the data and permitted the replication to be seen. Data saturation was achieved, categories became evident and theoretical thematic analysis was facilitated by thick and rich data.

Methods

Phase I. The first phase of Understanding aimed to meet Comstock's (1982) first hermeneutic step: "to develop an interpretive understanding of the intersubjective meanings, values, and motives held by all groups of actors in the subjects' milieu" (p. 380). Intersubjectivity is a socio-historical construct meaning the sharing of a collective reality with others and that understandings and actions are formed within a historical and social context, rather than being psychological attributes.

Interviews. Data collection began with interviews to understand practitioners' past experiences of OAM and dementia: participants described the OAM, the added complexities of

dementia, their perceptions of the family caregiver, the particularities of the home context, and their experience of professional agency.

Twenty-eight interviews were completed: urban (*n*=14), rural (*n*=8), and dual urban and rural coverage (*n*=6). Those participants who covered areas greatly impacted by winter weather were considered northern (*n*=18). Although most interviews were conducted face to face, winter travel challenges resulted in eight telephone interviews. Participant backgrounds were varied: nursing, social work, gerontology, recreational therapy and psychology. Their work experience primarily with older adults ranged from four to thirty-six years. There were no significant differences between the urban, rural, and northern participants in regard to length of service and experience. However, those with certain expertise might be based in an urban community while also ensuring coverage of a rural one. This description, including areas of expertise, is summarized in Table 1.

Table 1: Interview participants

Identifier	Rural/Urban/Northern or combination	Discipline	Years of experience	Expertise
1	Urban	Nursing	29	Dementia
2	Urban	Nursing	27	Geriatrics
3	Urban	Social work	22	Geriatrics
4	Rural/Urban/Northern	Nursing	5	Dementia
5	Rural/Urban/Northern	Gerontology	14	Psychogeriatrics
6	Rural/Northern	Nursing	18	Home care
7	Rural/Urban/Northern	Recreational therapy	9	Dementia
8	Urban/Northern	Nursing	19	Home care
9	Rural	Gerontology	16	Dementia
10	Rural	Nursing	14	Home care
11	Urban/Northern	Nursing	5	Home care
12	Urban/Northern	Nursing	4	Psychogeriatrics
13	Rural/Northern	Nursing	22	Home care
14	Rural/Northern	Nursing	7	Dementia
15	Rural/Northern	Nursing	20	Home care

16	Rural/Northern	Social work	31	Dementia
17	Rural/Urban/Northern	Social work	12	Psychogeriatrics
18	Urban/Northern	Nursing	36	Dementia
19	Urban/Northern	Recreational therapy	9	Dementia
20	Rural/Urban/Northern	Nursing	25	Psychogeriatrics
21	Urban	Psychology	20	Psychogeriatrics
22	Urban/Northern	Nursing	26	Dementia
23	Urban/Northern	Recreational therapy	10	Dementia
24	Rural	Nursing	6	Home care
25	Rural/Urban/Northern	Social work	8	Psychogeriatrics
26	Urban	Nursing	18	Home care
27	Urban	Nursing	24	Home care/Corrections
28	Urban	Gerontology	30	Dementia

At the onset of interviews, the information letter was reviewed with participants and any questions/concerns were addressed. A demographic information sheet (Appendix E) and consent form (Appendix F) were explained and completed. In-depth semi-structured interviews aimed to understand the embedded meaning of the professional experience of agency (Appendix G) (Broom, 2005; Carter & Henderson, 2005). Strategies to ensure rigor, as recommended by Morse (2015) were used: the collection of "shadowed data", information about what they generally knew about the phenomenon and the behavior of others (p. 1215); member checking, checking data between participants, as replication achieves reliability, and by verifying understanding with the participant by asking validation questions; and attempts to saturate any negative case, where important differences from the norm were identified.

Reflective journal. Next, as CST insists on self-reflection and self-understanding about the circumstances that restrain one's agency (Fulton, 1997; Maggs-Rapport, 2001), a reflective journal supplemented the interviews (Appendix H). Despite the benefits of interviews for data collection, participants might only reveal their "public accounts" and not share their "private accounts" which include true feelings and beliefs (Bowling, 2009, p. 409). Following

preliminary descriptive analysis of each interview transcript, further questions were sent by email to participants asking them to reflect on contextual influences on their experience of professional agency. Journals were sent by email and a reminder was sent after a two-week period. Nineteen of the twenty-eight journals were received (68% response rate). During interviews, most participants described very heavy workloads, especially those covering rural regions, possibly accounting for the lack of journal completion by all twenty-eight interview participants.

Although the journals were to initially consist of the same standardized questions for each participant, receipt of the first few journals revealed an absence of self-reflection and rather the presence of factual, objective answers possibly revealing what was socially and professionally expected of them. Journal questions were thereafter modified to encourage reflection upon their unique experience of meaningful intervention, control, and power in these cases (Freire, 1972; Frie, 2011). The result was positive as responses were transformed from cognitive-instrumental knowledge to moral-practical knowledge; the latter considered being a stepping stone to empowerment (Scheel et al., 2008). This method is congruent with CST research (de la Rue, 2003; Mantzoukas & Jasper, 2004) as it can: encourage a dialectical process revealing contradictions and ambiguities (Lyons, 1999); assist in identifying socially dominant structures and ideologies that have biased one's views, and meanings by which one makes sense of actions (Cash, Brooker, Penney, Reinbold, & Strangio, 1997; Comstock, 1982); and can promote self-nurturing, enlightenment and empowerment (Blake, 2005).

Inquiry focus groups. Thirdly, inquiry focus groups were conducted to achieve an intersubjective understanding, defined as a socio-historical construct and collective reality (Comstock, 1982). Participants invited to join focus groups were those who did not necessarily enter the home context, but who could provide insights into available community supports. In order to further understand the contextual influences on practitioners' experiences, and as

dialogue and empowerment are inherent to CST, the focus group method carries benefits of addressing power imbalances between the researcher and participants, empowering those whose voices have not been heard, and creating a synergy that produces data which would be less reachable without the group dynamics (Choudhry et al., 2002; Mkandawire-Valhmu & Stevens, 2010). Furthermore, focus groups facilitate probing of more complex and sensitive situations, such as OAM, and sharing with others who have lived similar experiences (Bowling, 2009; Kamberelis & Dimitriadis, 2011; Ruff, Alexander, & McKie, 2005).

Focus groups were held in the urban hub of a region and teleconferencing was arranged to permit more distant participants to join. At the onset of the focus groups, the primary researcher reviewed the letter of information (same for all Phase I methods), answered questions/concerns, and the demographic form (same for all Phase I methods) and consents (Appendix I) were completed. Prior to beginning the recording, members introduced themselves and chose a pseudo name to be used for transcripts. Facilitation approaches were used to create an atmosphere of acceptance, confidentiality and participation (Bowling, 2009). A hypothetical vignette, considered an effective means of encouraging sharing of beliefs, understandings and attitudes related to sensitive matter (Donovan & Sanders, 2005), was used (Appendix J). Based on CST, a discussion guide (Appendix K) facilitated an examination of rules, habits and traditions that they accept without question when dealing with such a case (Duffy & Scott, 1998).

To maximize data collection, a co-facilitator assisted in the management of focus groups including taking detailed field notes and documenting observations of interaction among participants (Kidd & Parshall, 2000). A regional consultant acted as co-facilitator. Known and trusted by practitioners in the Northeastern Ontario region, her presence increased comfort and facilitated sharing.

Despite the recommended number of participants in a focus group of 6-12 (Bowling, 2009), these numbers could not be reached due to human resource challenges within participants' organizations. Group sizes varied and despite the smaller size of some groups, varied discipline representation and much experience with OAM resulted in rich discussion. With the exception of six interview participants with significant case exposure who chose to also join the focus groups, participants in the latter differed in that their work was primarily outside of the home, providing community health supports, social services and criminal enforcement to practitioners within the home. Table 2 summarizes the regions represented, the number of participants, years of experience of the participants, and the various disciplines represented in the focus groups.

Table 2 : Inquiry Focus Groups

Identifier	Rural/Urban/Northern or combination	*n*=29	Years of experience	Disciplines represented
1	Rural/Urban/Northern	9	6-22	Nursing, Criminology, Psychogeriatric, Domestic abuse, Social work, Gerontology
2	Rural	4	10-35	Nursing, Social work, Gerontology, Domestic abuse
3	Rural/Northern	6	5-31	Criminology, Gerontology, Nursing, Business administration
4	Urban	3	10-20	Social work, Criminology
5	Urban	7	1-42	Social work, Health, Gerontology, Nursing, Corrections

Interim report. Once all interviews, reflective journals, and inquiry focus groups were completed, a preliminary descriptive analysis resulted in the production of an Interim report (Appendix L). The report was mailed to all participants regardless of their verbalized intent to continue participation into the Empowerment phase. As this study was viewed as a process of discovery, validation of experiences, critical reflection, progressive enlightenment, collaboration, and action, analysis sharing with participants throughout the study was important.

Unexpected positive outcomes of sharing this report were an enhanced understanding and thematic analysis for the primary researcher, established credibility of the initial analysis from participant validation (Koch, 2006) and a greater collective strength to collaborate on action projects resulting from the communicative action of shared meanings and interpretations (Habermas, 1976). Recognizing their own experiences in those of others as described in the report provided transformative strength (Bevan, 2013).

Phase II. The second phase of the study, the Empowerment phase, was one of action to bring about new understandings and change (Comstock, 1982).

Action focus groups. As the emancipation desired in this action phase required dialogue and engagement, action focus groups brought together all participants from a geographical region who participated in interviews and in inquiry focus groups (Fontana, 2004; Freire, 1972). This method, combining insights about OAM in the home with knowledge of community supports outside the home, was able to replicate the dynamics of everyday life social interactions for these practitioners who, ideally, would come together to manage cases of OAM (Kamberelis & Dimitriadis, 2011). The goal was to achieve richer, more complex and collaborative understanding (Choudhry et al., 2002). The focus group was an ideal dialogical tool to facilitate reflection, to develop emancipatory knowledge, and to empower participants to act (Freire, 1972).

As participation in this focus group took a new form of group engagement, a new consent was obtained (Appendix M). Appendix N guided the pedagogical and political action discussion. Due to significant human resource challenges in one region, action focus groups were only held in four of the five geographical areas. Table 3 summarizes the regions represented, the size of the groups, the years of experience of participants, and disciplines represented.

Table 3 : Action Focus Groups

Focus group	Rural/Urban/Northern or combination	*n*= 31	Years of experience	Disciplines represented
1	Urban	9	1-30	Nursing, Criminology, Psychogeriatric, Social work, Gerontology, Corrections
2	Rural/Northern	5	9-31	Criminology, Gerontology, Nursing, Recreational therapy, Social work
3	Rural/Urban/Northern	5	5-25	Nursing, Criminology, Gerontology, Domestic abuse
4	Urban/Northern	12	4-36	Nursing, Business administration, Domestic abuse, Recreational therapy, Social work

Using the "pedagogical function" of focus groups, the pedagogy of Freire (1972) provided a model for an education component. Emancipatory knowledge was created as participants' self-awareness of their collective potential increased. The interaction among group members elicited further data as practitioners learned about their shared challenges, built upon one another's experiences, critical consciousness was raised and praxis occurred (Kamberelis & Dimitriadis, 2011). In these action focus groups, participants were encouraged to question and imagine possibilities "to keep the inner tension between illumination and concealment" alive (Nuyen, 1994, p. 431).

Then, using the "political function" of focus group work, participants were encouraged to form a "critical mass of visible solidarity… (to enact) social and political change" (Kamberelis & Dimitriadis, 2011, p. 552). Participants were asked to consider alternatives to their present situation, to think dialectically, of what could be (Boychuk Duchscher, 1999). Dialogue followed, where all participants were encouraged to assess the findings from their colleagues in the five geographical regions and equally contribute to possible action projects (Fulton, 1997). To provide participants with new ways of seeing their situation, the researcher presented a visual

model of empowerment (Figure 1) offered by Delp, Brown, & Domenzain (2005). The model is meant to demonstrate the cyclical nature of individual empowerment, organization and community empowerment, and resulting community/policy change. This was instrumental in assisting participants to think beyond current barriers. In this last phase, the goal was to assist these champions to gain the power to "reinforce a common sense of agency" (Mkandawire-Valhmu & Stevens, 2010, p. 688).

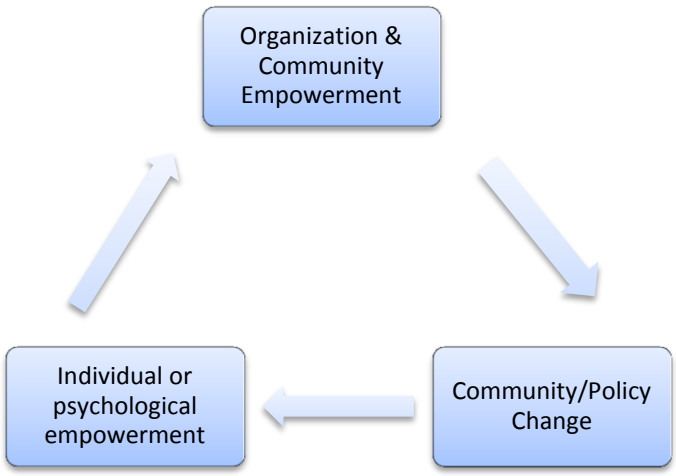

Figure 1: Relationship between Levels of Empowerment and Community/Policy Change (Delp, Brown, & Domenzain, 2005) (Reprinted with permission)

Final report. Once all action focus groups were completed, a final descriptive analysis resulted in the production of a Final report (Appendix O). The report was mailed to all participants. This dissemination, initially incorporated into the study design to uphold key values of reciprocity and power-sharing (Grant & Giddings, 2002), was essential to sensitize all stakeholders to the experiences of front-line practitioners, their recommendations for the field, and the action projects to which they were committed. It also served to connect the five geographical regions creating one Northeastern Ontario voice.

Overall, in Phases I and II, twenty-three Northeastern Ontario organizations were included and fifty-one practitioners participated. The names of these organizations are not

disclosed to protect participant confidentiality as those in small rural regions might be the sole representative of an organization, and to address the concerns of some organizations that policies regarding OAM would be revealed and critiqued.

Ethical considerations

Ethical approval was obtained by the Laurentian University Research Ethics Board (Appendix P) as well as the ethic committees/administration of participating organizations (Appendix Q). Although practitioners may encounter such cases in their everyday work life, a concern was that sharing could elicit distress. Each interview and focus group therefore concluded by reviewing the contact information of the organization's employee assistance program.

Prior to any data collection, the legal considerations of sharing information regarding OAM were explained. In Ontario, there is no legal responsibility to report OAM as there is no adult protective legislation. However, participants were informed of existing pertinent legislation (Appendix R) if an older adult or caregiver is at significant risk of serious bodily harm, violence, suicide, or imminent danger (CCEL, 2011b). To prevent the sharing of active cases, participants were asked to only share past cases of OAM. As questions could arise in the focus group setting, the regional consultant, who was co-facilitating the focus groups, listed community resources that practitioners may pursue for their cases (Appendix S). The organizations were not informed of which employee participated.

Interviews and focus groups were audiotaped. Audio recordings were password protected and transcripts stored in a locked filing cabinet in the researcher's locked office, located in the School of Nursing, Laurentian University. Consents were stored separately using the same precautions. All audio data will be destroyed once findings are published. All paper records will be shredded then cross shredded after completion of the study. Journals were coded to protect

participants' confidentiality. In any knowledge dissemination activity, reported cases were anonymized.

Theoretical Thematic Analysis

A theory-led thematic analysis was performed on the data from all research methods (Braun & Clarke, 2006). Driven by CST, focus was placed on interpreting the participants' underlying meanings, values, and aims and contextualizing them within the social practices and structures that produce, uphold and reinforce them (Comstock, 1982). Three components were kept at the forefront: the previously stated research sub-questions on the practitioners' experience of professional agency with these cases and their underlying beliefs, understandings, and motives; CST inspiring theoretical interests of influencing ideologies, dominant structures, self-reflection and empowerment; and the primary researcher's analytic preconceptions regarding research-policy-practice gaps in this field.

As data collection spanned eight months and required much travel, field notes provided a record of perceptions and thoughts about decisions, the data, and analysis (Morrow & Smith, 1995; Morse & Richards, 2002). As participants spoke in interviews and focus groups, brief notes of striking answers were taken, leading to clarification seeking, deeper thought and further inquiry. Post-interview, thoughts about the interview or focus group, particularities to remember, any modifications required to the interview guide or the process, and common identified patterns were noted. These field notes, considered part of the data corpus for analysis (Morrow & Smith, 1995), complemented the interview and focus group transcripts, and reflective journals.

Data immersion, the first step of analysis (Braun & Clarke, 2006), consisted of repeated readings of the paper transcripts, annotating them, and thinking about the data conceptually. This pen and paper process of annotation was instrumental in creating preliminary conceptual maps which served two important functions: visually representing the data, and clarifying researcher

preconceptions with this phenomenon in order to recognize their possible influence on the analysis (Comstock, 1982; Nuyen, 1994).

Next, initial coding frameworks were created based on the first interviews. Using an iterative process, these initial frameworks were then continuously revised, considering the data from all participants and all data collection methods, with the goal of identifying shared meanings and experiences (Braun & Clarke, 2006). NVivo 11 was used to organize data extracts into these codes. Further annotation was carried out electronically and memos were entered when repeated patterns were noted across interviews. Three final coding frameworks, representing three key themes evolved: the experience, the influence of contexts, and the need for empowerment (Appendix T, Appendix U, and Appendix V)

After 6 months of data collection, a descriptive level analysis was performed on the data, with the aim of producing an Interim report for participants as previously mentioned. This report was instrumental for numerous reasons: participants voiced that the report validated their experiences; that it was empowering to learn that colleagues in all five geographical areas had similar experiences; and that reading it propelled them to participate in the Action focus groups in the Empowerment Phase.

Then, analysis was pursued at a deeper latent level versus descriptive surface meanings (Braun & Clarke, 2006). This interpretive analysis was greatly assisted by four processes: reviewing conceptual maps created during the annotating of paper transcripts; reviewing field notes; memoing while reviewing codes which further conceptualized data patterns and; returning to the CST literature to ensure an in-depth theoretical analysis of the data (Braun & Clarke, 2006; Tuckett, 2005). The products of this interpretative analysis were three candidate thematic maps outlying candidate sub-themes related to the three key themes of experience with OAM and dementia, the influencing contexts, and need for empowerment. These maps were then refined to ensure themes were thick and rich with supportive data, coherent, and discreet. This

final step entailed returning to the entire data set and considering the validity of the themes in all three thematic maps.

The three key themes of the experience, the influence of contexts, and the need for empowerment represent the knowledge that informed the action participants chose to pursue. Figure 2 illustrates how the chosen actions address the intersection of OAM experiences challenged by contextual influences where participants felt disempowered.

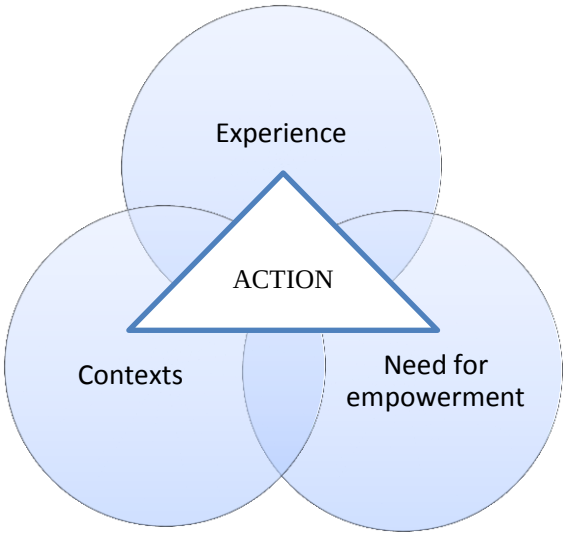

Figure 2: Knowledge-informed action

Conclusion and Overview of Subsequent Chapters

Mistreatment, of an older adult with dementia, by their family caregiver and within the home, is a social phenomenon that threatens to amplify but yet remains under researched. Those practitioners who are exposed to these cases within the home must manage them within complex contexts including health and social services, geographical influences, and legal complexities, none of which has been sufficiently addressed in the literature. The voice of these practitioners are seldom heard nor are their recommendations to improve outcomes for the older adults and caregivers in their care. This integrated-article thesis attempts to rectify these research-practice-policy gaps. A two-phase qualitative critical inquiry, utilizing a CST lens, used methods of interview, reflective journals, and inquiry and action focus groups with practitioners from 23

organizations in Northeastern Ontario. Theoretical thematic analysis identified themes relating to the experience of practitioners with OAM, dementia, and the family caregiver in the home, the contexts that impact this experience, and actions proposed to improve practice, policy, and outcomes for mistreated older adults.

Chapter 2, a paper entitled *Reflecting on mistreatment of older adults with dementia within the home using a Critical Social Theory lens: Self-discovery and unattainable professional agency*, presents the experience of practitioners who encounter mistreatment of an older adult with dementia by a family caregiver in the home. Specifically, it explains the experience of 'professional agency', the ability to control outcomes and provide meaningful intervention. Data from semi-structured interviews with practitioners representing diverse disciplines and organizations, complemented by personal reflective journals, as well as inquiry and action focus group discussions, were analyzed using a theory-led thematic analysis. Analysis led to the identification of five sub-themes (Figure 3): weathering the storm to realization; cognitive uncertainty; emotional upheaval; one's inability to resolve; and the double-edge sword of self-reflection. Themes are depicted as steps; bullets next to some steps represent factors that drew participants out of that step; an arrow represents the power of reflection on the entire process; partial professional agency was achieved in limited circumstances which will be illustrated in the analysis. Understanding the experience of professional agency with these cases was the first step towards situating this experience within its contexts, and later striving for improvements to policy and practice.

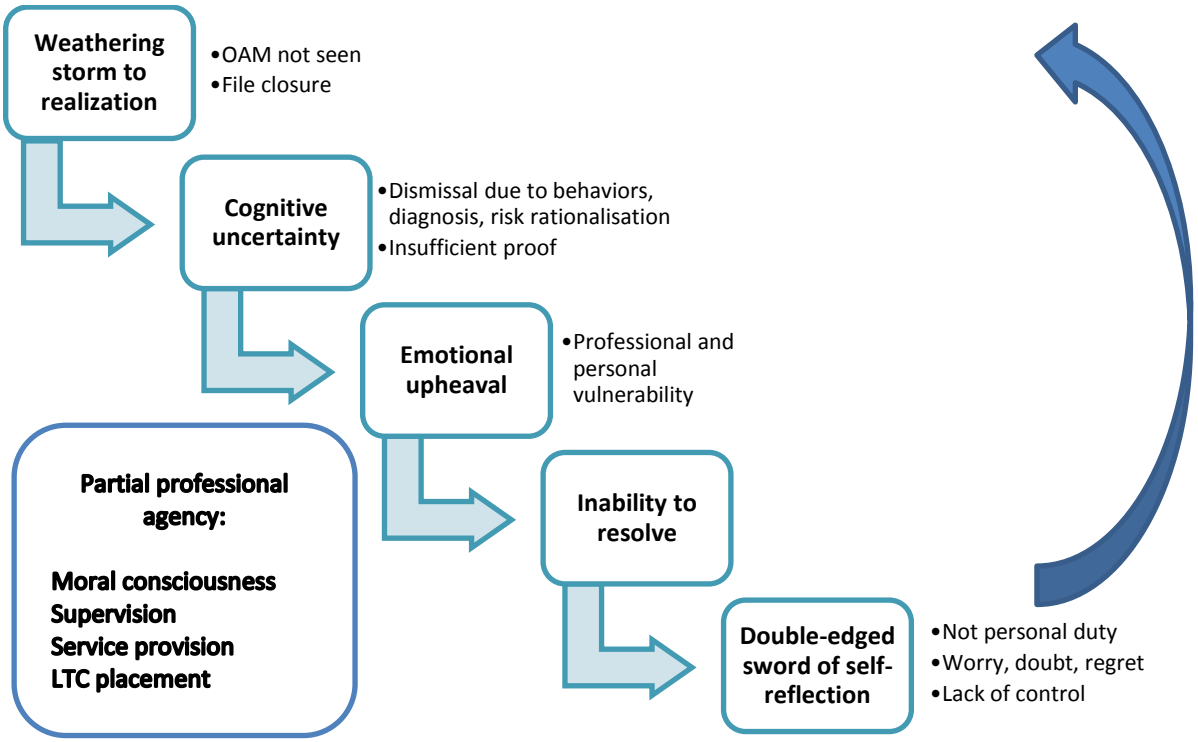

Figure 3: The experience

Chapter 3, a paper entitled *The professional experience of mistreatment of older adults with dementia within the home: Oppression within socio-political, health care, and geographical contexts in Northeastern Ontario, Canada*, exposes how context influences this experience. More specifically, a critical exploration of the influence of the socio-legal, geographical and health system contexts on this experience was undertaken. This paper situates the experience of social services, health care, and correctional practitioners from rural and urban Northeastern Ontario communities within the contexts of their communities and province. The methods of semi-structured interviews, reflective journals, and inquiry and action focus groups facilitated open discussion, the creation of a synergy, and reflection upon prevailing ideologies within the socio-legal, geographical and health system contexts. A theoretical thematic analysis led to the identification of five sub-themes (Figure 4): the privileged burden of seeing behind closed doors; a domestic problem within a societal context; interprofessional imperative with an impossible problem; history of stagnation, losses, and systems failure; and legislative complexity and

oppression. Sub-themes are depicted as contexts, situated within, and therefore impacted by larger contexts. Viewing this phenomenon through a CST lens elucidates oppression from these contexts upon the practitioners, who, although entrusted to intervene in cases of OAM, report powerlessness within them. Understanding how these contexts are oppressive is a required step towards changing this contextual reality.

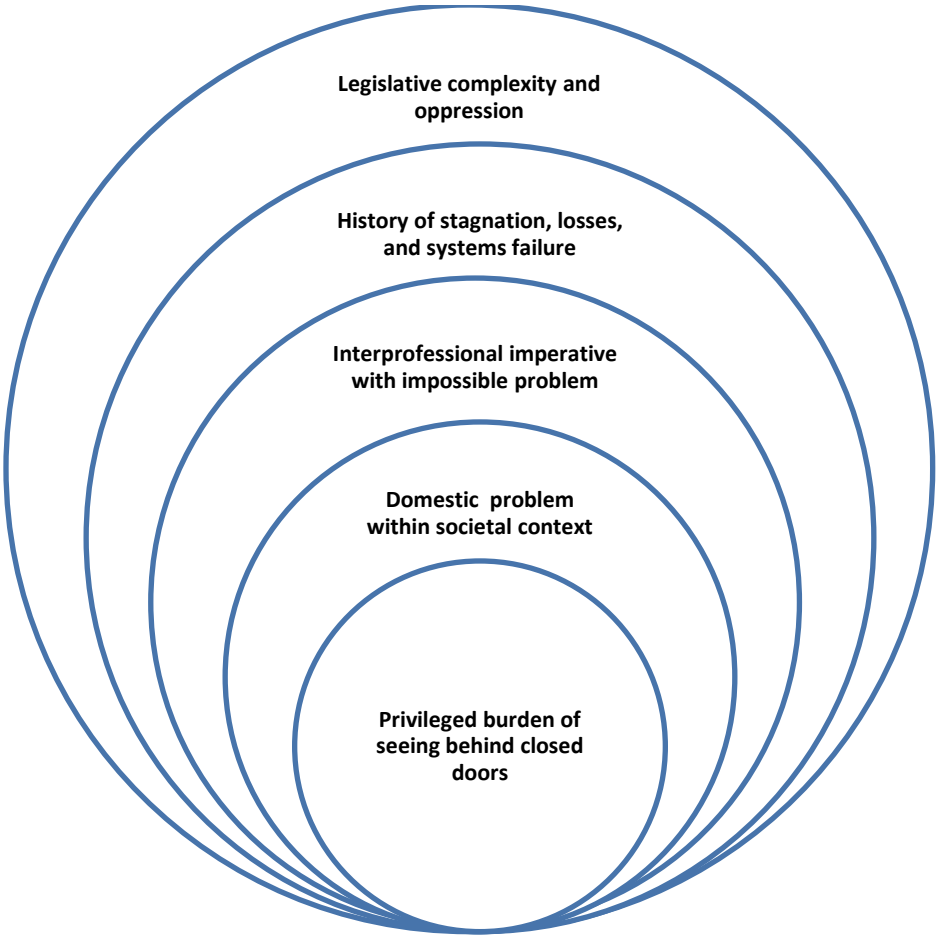

Figure 4: Contextual influences

Chapter 4, a paper entitled *Practitioner empowerment in cases of OAM and dementia: A critical methodology to take action to promote professional agency*, presents actions proposed by health care, social services and correctional practitioners, who, experiencing powerlessness within the current Northeastern Ontario oppressive contexts, proposed innovative projects to improve practice, policy, and outcomes. Here, the work of Freire on oppression and

empowerment guided focus group discussions in urban/rural communities of Northeastern Ontario bringing together participants from twenty-three organizations. Theoretical thematic analysis of data collected during this two-phase study revealed four sub-themes: “We” need empowerment; Is team empowerment possible?; Legislation and infrastructure are imperative; and Cautious optimism. A thematic map (Figure 5) is presented as a process demonstrating the gradual empowerment of these practitioners who have historically struggled with these cases and contexts.

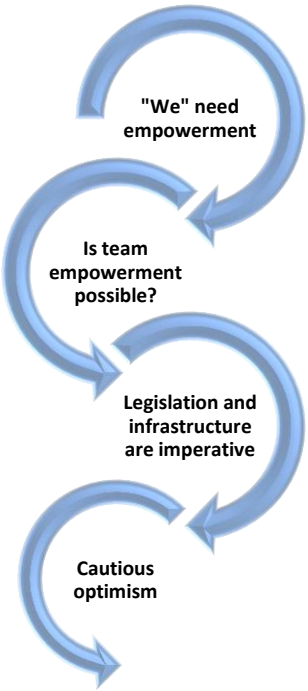

Figure 5: Practitioner empowerment

Five projects were decided upon by the participants who experienced renewed hope that these actions could serve to increase their professional agency, that of their teams, the well-being of older adults with dementia and their communities, as well as advance policy, practice, and research in the field of mistreatment and dementia.

Finally, Chapter 5 highlights key knowledge developments, limitations of the study and offers recommendations for policy, research and practice for the field of OAM and dementia, concluding with the significance of the study.

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Chapter 2: Mistreated older adults with dementia in the home: Practitioner experience and unattainable professional agency

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Introduction

Older adult mistreatment [OAM], commonly referred to as elder abuse, is defined as "actions and/or behaviours, or lack (thereof), that cause harm or risk of harm within a trusting relationship" (McDonald, 2015, p. 6). When the mistreated older adult also has dementia, numerous factors increase the risk of OAM including impaired expressive language, motor skills, and decisional capacity, as well as behavioural and psychological symptoms of dementia (Alzheimer Society of Canada, 2010). Although international prevalence rates range from 0.8-36.2% for older adults without cognitive impairment (McDonald, 2015), when considering older adults with dementia living at home with a family caregiver, prevalence rates rise sharply to 34.9-62.3% (Sasaki et al., 2007; Yan & Kwok, 2011).

The phenomenon of OAM perpetrated by a family caregiver within the home reveals an uncomfortable paradox: a provincial home care system's overreliance on informal caregivers (McMaster University, 2014), where studies demonstrate that in 85-90% of OAM cases, it is precisely these adult children or spouses who victimize older adults (Amstadter et al., 2011; Choi & Mayer, 2000; National Center on Elder Abuse, 1998). Therefore, it is important to study dementia and OAM by a family caregiver, with whom there is a pivotal relationship of responsibility for care or protection (National Research Council [NRC], 2003).

Mistreatment of older adults living at home which remains hidden from societal scrutiny is allowed to increase in gravity (World Health Organization/ International Network for the Prevention of Elder Abuse [WHO/INPEA], 2002). When occurring in the community, the OAM

will possibly only be discovered by formal practitioners who visit the home (Carp, 2000). Studies have revealed challenges experienced by practitioners in OAM cases with older adults without cognitive impairment (Beaulieu & Leclerc, 2006; Bergeron, 1999; Omote, Saeki, & Sakai, 2007). However, little is known about the experience of the formal care practitioners who support mistreated older adults with dementia and their caregivers in their homes. This study aimed to understand this experience, situate it within the contexts of Northeastern Ontario, Canada, and facilitate practitioner empowerment towards policy and practice change. This paper offers findings on this experience, knowledge that is crucial to understanding practitioner intervention with OAM and dementia and to influencing policy required to support these practitioners in their vital role with mistreated older adults.

Studies with practitioners in OAM cases have depicted a burden of sole responsibility and fear in these cases, countertransference of professional helplessness onto the mistreated older adult, and ethical dilemmas (Bergeron, 1999; Dong, 2012; Killick & Taylor, 2009; Mixson, 1995; Sandmoe & Kirkevold, 2011; Wilson, 2002). In Canada, where the majority of provinces do not have adult protective services, only two studies have explored this experience: Quebec research teams Lithwick, Beaulieu, Gravel & Straka (1999) and Beaulieu & Leclerc (2006) revealed the complexity of challenges in these cases that participants needed to "carry alone" (p. 180). In the province of Ontario, the context for this study, where there is no adult protective legislation or infrastructure, the practitioner experience is unknown.

Internationally, a handful of studies have been conducted in socio-legal contexts similar to Quebec and Ontario: in Japan, the control of the mistreating caregiver was described (Omote et al., 2007); in Sweden, practitioners based their decisions on intuition and vague cues (Saveman, Hallberg, & Norberg, 1993); and admitted to tolerating mistreatment (Erlingsson, Carlson, & Saveman, 2006); while trying to remain neutral (Saveman, Hallberg, & Norberg,

1996); and to considering the importance of family in decision-making (Erlingsson, Ono, Sasaki, & Saveman, 2012).

Furthermore, the experience of practitioners working in rural regions has received little attention in the literature. Although most studies have taken place in the United States (Amstader et al., 2011; Buckwalter, Campbell, Gerdner, & Garand, 1996; Dimah & Dimah, 2003; Vandsburger, Curtis, & Imbody, 2012), some researchers in Australia (Cupitt, 1997), the United Kingdom (Cornes, Manthorpe, & Haselden, 2010), Spain (Garre-Olmo et al., 2009), and China (Wu et al., 2012) have also focused on OAM in the rural setting. In Canada, few studies have been conducted: the work of Harbison, Coughlan, Karabanow and VanderPlaat, (2005) contributed to some exploration of practitioner experience but within an infrastructure of adult protective legislation; MacKay-Barr & Csiernik (2012) described types of OAM and some characteristics of mistreated rural older adults and their relationship to their perpetrators; Stones & Bédard (2002) revealed higher rural thresholds of acts considered to be OAM; and Weeks, Richards, Nilsson, Kozma, & Bryanton (2005) identified dementia and isolation as characteristics of their mistreated rural sample. Therefore, what rural and northern practitioners experience in cases where dementia and OAM collide, in a province without adult protective legislation, remains unknown.

The professional experience of encountering OAM in the home has been eloquently described by Anetzberger (2005) as an assault on the senses. Alhough a practitioner might not feel that action is possible in such intolerable situations (Fulton, 1997), professional accountability is socially expected (Beaulieu & Leclerc, 2006). In the absence of intervention, negative outcomes such as increased mistreatment or older adult death may result (Lachs, Williams, O'Brien, Pillemer, & Charlson, 1998; NRC, 2003).

The voices of formal care practitioners involved in complex cases of mistreatment are seldom heard. This study is focused on a specific component of their professional experience,

that of professional agency, defined by Frie (2011) as: "an emergent, affective, and cognitive process that permits us to respond to our situations in meaningful ways" (p. 341). A lack of professional agency is reflected in the handful of studies that have explored professional decision-making in cases of OAM: formal practitioners frequently may feel powerless to intervene (Beaulieu & Leclerc, 2006; Omote et al., 2007). When practitioners encounter OAM in the home setting, their professional agency, the "human capacity for reflective action and choice" (Frie, 2011, p. 341), is constrained. To the authors' knowledge, no study has explored the formal practitioner's sense of professional agency with OAM.

Therefore, due to the higher prevalence rates of mistreatment of older adults with dementia, the current shift from institutional care to home care by family caregivers, the complexity of cases, and the gravity of consequences, the experience of professional agency in these cases must be explored.

Study Purpose

This critical inquiry pursued three incremental aims: to learn how health care and social services practitioners, who visit the home, experience professional agency when older adults with dementia are mistreated by their family caregiver; to discover how this experience is impacted by the contexts within which it occurred; and to propel practitioners to action to improve practice, policy, and ultimately, care for older adults in their home. This paper presents the first step above, that of understanding the experience of professional agency, as described by practitioners who shared their past cases. The second and third aims are reported elsewhere (Lindenbach, Morgan, Larocque, & Jacklin (in preparation); Lindenbach, Larocque, Morgan, & Jacklin (in preparation).

Methods

This two-phase study began with a phase of understanding an experience and the contexts within which it occurred, followed by a phase of empowerment to learn and act upon that understanding. Data resulting from both phases are analysed and presented in this paper.

Theoretical Underpinnings

Viewing this experience through a Critical social theory [CST] lens (Habermas, 1971, 1976) was essential to analyzing, critiquing, and deconstructing both influencing ideologies and societal structures as well as to guiding participants in an internal critique involving reflexivity and dialogue (Fontana, 2004). Critical inquiry is based on historical realism which asserts that reality is virtual in that it is constructed and imposed upon us by socially dominant structures (Lincoln, Lynham, & Guba, 2011). Therefore, beliefs, values and assumptions are not necessarily one's own, but instead have been adopted from powerful ideologies and structures in society that have crystallized over time. It therefore fits within a contextualist paradigm as experience cannot be understood without examining its context (Maggs-Rapport, 2001).

The foci of the critical researcher's attention are the experiences and voices of the disempowered (Grant & Giddings, 2002). At first glance, the health and community care participants chosen for this study may not appear to be disempowered. However, the hypothesis of disempowerment is supported by literature which implies that practitioners lack knowledge in this field, or ignore OAM, and a lack of knowledge and policy guidance for complex cases when the older adult has dementia.

Habermas' (1976) concept of moral consciousness also inspired this study. Given the sensitive nature of mistreatment by a caregiver of an older adult with dementia, the "interactive competence for consciously dealing with morally relevant conflict" guided the analysis of participant beliefs, values, and motives (p. xxi).

Lastly, although Critical theory is rooted in hermeneutic philosophy which seeks to interpret people's meanings of their world (Comstock, 1982), Habermas explained the necessity not only to interpret lived experience but to strive towards emancipation and change (Jacobs, 2014). To achieve this emancipatory agenda, the work on critical consciousness of Freire (1972) inspired the study.

Methodology

Critical theory research begins with a process of self-reflection (Duffy & Scott, 1998) which is fundamental to overcoming the researcher's preunderstandings (Jacobs, 2014). Therefore, when designing this study, the primary researcher (first author) journaled her experiences with OAM by a family caregiver. Then, as critical science is openly ideological (Fontana, 2004), the following beliefs guided this study: that an inquiry into this experience and its contexts must dig beneath the usual surface presented in most prior quantitative studies; and that collaborative efforts between researchers and practitioners must take the form of a political activity. Next, dialogue, Habermas (1976) explained, is the path through which CST can reach a mutual understanding of truth. Dialectic thinking, the third component of CST, facilitates the examination of contradictory values, interests, and conditions (Fontana, 2004). Therefore, in this study, chosen methods aided participants to engage in critical self-reflection, share their stories with the researcher, and dialogue with their peers.

Sampling

Sampling aimed to obtain a purposive sample of practitioners willing to share their experience of agency in a past case of mistreatment by a family caregiver of an older adult with dementia in the home. The term 'practitioner' encompasses health and social care, community services, and police enforcement who are involved in varying degrees with OAM and dementia cases. As the study unfolded, further snowball interviews were completed. Five Northeastern Ontario geographical districts were reached. For this study, rurality was defined using the Rural

Small-Town definition: “towns or municipalities outside the commuting zone of larger urban centres (with 10,000 or more population)” (du Plessis, Beshiri, Bollman, & Clemenson, 2001). Applying this definition to data from the 2011 Canadian Census, regions were classified as either rural or urban. Next, although all areas of Northeastern Ontario are considered “northern” (Health Quality Ontario, 2017), with harsh winters lasting approximately six months in this area, for the purpose of this study, regions were only considered “northern” if winter closures of Trans-Canadian highways prevented access to these communities. Practitioners stressed the importance of this factor in their ability to care for the older adults/caregivers in their care. Numerous backgrounds were included: nursing, social work, gerontology, recreational therapy, psychology, physical education, business administration, criminology, and corrections. Work experience primarily with older adults ranged from one to 42 years. Considering the complete study, 23 Ontario organizations are included.

Ethical approval was obtained from the Laurentian University Research Ethics Board and the ethics committees of all participating organizations. The names of these organizations are not disclosed to protect participant confidentiality as those in small rural regions might be the sole representative of an organization, and to address the concerns of some organizations that policies regarding OAM would be revealed and critiqued.

Phase I: Understanding

Interviews. In-depth semi-structured interviews with practitioners having access to the dyad in the home served to understand the embedded experience of professional agency (Carter & Henderson, 2005). Participants were asked to share a past case of mistreatment of an older adult with dementia by an informal caregiver; beliefs, values, and motives were questioned; and questions exploring the concept of professional agency followed. Twenty-eight interviews were conducted, lasting 1-1.5 hours, with the majority being face-to-face. Table 1 describes participant characteristics and provides an identifier code used in reporting the Results.

Reflective journaling. A reflective journal supplemented the interviews. After a preliminary analysis of their interview, questions in a reflection guide were forwarded to participants, with a reminder after two weeks. Nineteen journals were received (68% RR). During interviews, most participants, especially in rural regions, described very heavy workloads, possibly accounting for the noted attrition.

Inquiry focus groups. Driven by CST, it was necessary to contextualise the participants' underlying meanings, values, and aims within the social practices and structures that produced and reinforced them (Comstock, 1982). Focus group participants primarily worked outside of the home and could therefore provide insights into available community supports in these cases. To set the stage for the focus group discussion, a hypothetical vignette was used.

The ideal number of participants in a focus group ranges between six to 12 (Bowling, 2009). Given human resource challenges with certain of the practitioners' organisations, reaching these numbers was challenging. Teleconferencing was arranged to permit more distant participants to join. Group sizes varied (n=3 to 9). Despite the smaller size of some groups, varied discipline representation and much experience with OAM resulted in rich discussion. Table 2 describes focus group composition as well as an identifier used in the Results section.

Phase II-Empowerment

Action focus groups. Thirty-one practitioners who participated in the Understanding phase chose to continue participating in the Empowerment phase. Action focus groups facilitated discussion leading to greater collaboration between those practitioners exposed to OAM within the home, and those providing supports outside of the home. The action projects they chose to undertake have been described elsewhere (Lindenbach et al., in preparation).

Theoretical Thematic Analysis

Theoretical thematic analysis, proposed by Braun & Clarke (2006), was carried out. As analysis is an iterative process throughout the study, raw data and preliminary researcher analysis

were offered during subsequent interviews and focus groups thus pursuing deeper reflection and discussion. Data collection spanned eight months and field notes were created (Morse & Richards, 2002). Analysis began with data immersion. Then, using the research sub-questions, the theoretical framework, the primary researcher's analytic preconceptions, and first interviews, initial coding frameworks were created. NVivo 11 was used to organize data extracts into these coding frameworks. Throughout analysis of interview, reflective journal, and inquiry and action focus groups data, these initial coding frameworks were constantly revised, resulting in three final coding frameworks of three key themes: the experience of professional agency, the influence of contexts, and the need for empowerment. As this paper focuses on the first key theme of the experience of professional agency, that coding framework is provided in Appendix 1. Next, to achieve an interpretive level of analysis, the primary researcher reviewed all coded data and electronic annotated data excerpts to create memos of repeated patterns across the data. As a result, candidate sub-themes were identified for each of the key themes of experience, contextual influences, and need for empowerment. These were then repeatedly refined resulting in thick and rich sub-themes. This paper draws on the data from the two-phase study but presents the data filtered through the key theme of the experience.

Rigour

Three principle strategies were used to enhance rigour. Firstly, the heterogeneity of the sample resulted in rich and thick data, in which all participants, regardless of discipline, could instantly recognize the phenomenon of mistreatment of an older adult with dementia by an informal care giver within the home. Morse (2015) refers to this ability of instant recognition of the phenomenon as "demonstrated reliability" (p. 1218). Secondly, Morse (2015) suggests demonstrating evidence of self-reflection on how one's own experiences affect data interpretation. Throughout analysis, the first author continued to apply the process of self-reflection on preunderstandings and the experiences of participants. The repeated modification of

a conceptual map was an excellent tool to visually demarcate the two ensuring that these preunderstandings did not influence the findings. Thirdly, raw data and preliminary researcher analysis from interviews was offered during subsequent interviews and focus groups thus pursuing deeper reflection, discussion, analysis, and serving as a form of member checking (Tuckett, 2005).

Results

Analysis led to the identification of five sub-themes (Figure 1): weathering storm to realization; cognitive uncertainty; emotional upheaval; inability to resolve; and the double-edge sword of self-reflection. Sub-themes are depicted as steps; bullets next to some steps represent factors that drew participants out of that step; an arrow represents the power of reflection on the entire process; partial professional agency was achieved under limited circumstances.

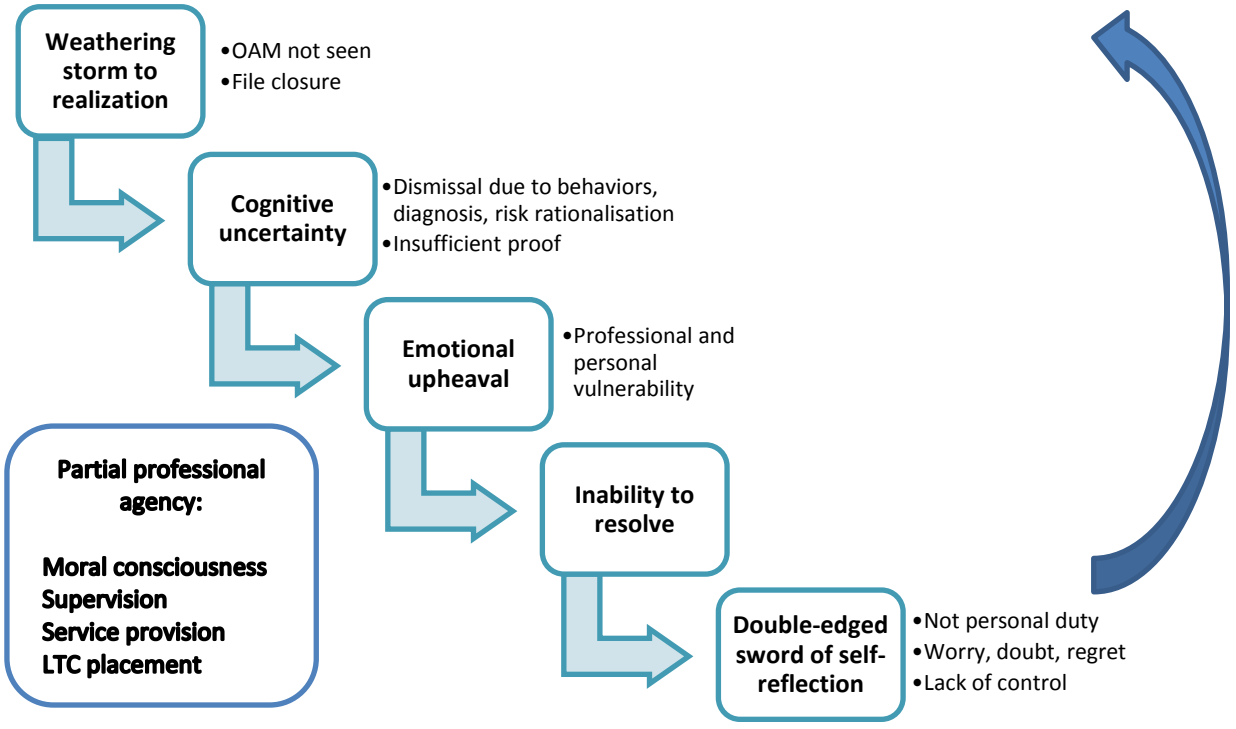

Figure 1: OAM, dementia, reflection and professional agency

Weathering Storm to Realization

When confronted with OAM in the home, a visceral bombardment and loss of professional grounding were described. This participant explains her instinctual reaction to escape the storm but instead, her decision to remain in it, because professionally, she could not escape this reality.

> Your heart is beating and your hair is standing up on end, all of those things that we feel, this is so not good, but I'm staying here, and I probably shouldn't, and your head's going 20, 000 different directions, and you want to run, but you don't, and you can't, and you're not going to, and then you're calm, you elicit that whole piece, and then you leave, and you're shaken. (FGIIU4)

Fellow focus group participants empathetically echoed the physical and psychological vulnerability of this experience: "I don't know (sigh) I never feel like I am ready for anything like this. Even after all of these years in nursing…" (NurUN6). This admission of vulnerability, a contradiction of professional stature social expectations, permitted others to share.

During this bombardment, fear was evidenced in their recollections of past cases; speech was hurried as they rushed through thoughts and actions. In some cases, this fear was elicited by an aggressive caregiver: "Going to the home set off alarms…because of his stature standing there … how it would escalate and he was answering for her…He was higher strung…very paranoid and she would clamp down" (NurRN13).

Being in the home, where safety could not be ensured, also elicited fear:

> He took his mom into a really bad situation… a shack…. with a wood burning stove. I thought, you leave your mom out here, in the middle of winter… alone for hours. She had no way of getting help… He had to lift her out of bed …some nurses had seen drugs. When I went… first step in the house, there was three or four big dogs, and I thought, (pause) ok (hesitation)…. (NurRN6)

As this rural participant spoke, she straightened her posture demonstrating physical composure, perhaps reflecting her actions that day when entering this isolated home. Despite the possible danger, she felt obliged to enter as her patient was possibly mistreated.

Facing this fear despite danger was perceived as a mark of dedication:

> There had been some incidents with him and the PSWs as well. So, he was very aggressive, had made sexual innuendo advances. But the lady needed the help, so they went, the diehards, went for her. (GerR9)

Going into a home where mistreatment was possibly occurring triggered an intuitive alarm that could not be ignored. A social worker of 25 years reflected:

> Still to this day, there are times where you go into someone's home and things don't feel right, and there is something off…and you think, something is going on here but I can't put my finger on it. And then you leave, and that is all you can think about. (SWU3)

Reflecting on confirmations of past mistreatment cases was validating. The ability to trust this intuition provided grounding, an ability to remain in the storm, and a strength, although uncomfortable, which developed with exposures to this storm. Not all recognized this intuitive alarm. Some participants felt the need to justify this alarm:

> If you count decisions made on past experience, I don't consider that a feeling. Yes, I get a gut feeling that something's wrong but it's usually based on patterns that I've seen before or you know 10 years' experience … I'd call it (intuition). (FGIIRN3)

Participants donned a professional armor of sorts, which served two purposes: to remain calm and not display fear, thereby protecting the older adult, and to protect themselves from the vulnerability of this required exposure which left them shaken. Some did not realize this strategy until reflecting upon past cases. A participant described, very calmly, the measure she took to ensure her safety:

> The nurse was scared…I was worried more for her (older adult). I could hold my own ground with him. I did however have my cell phone opened to the dial pad. As soon as I swiped it open, I could call 911. (researcher: Do you do that with all patients you visit at home?) No, just the ones that the alarms go off… I think he is the only one that I have ever been leery about being alone with. (NurRN13)

This recognition surprised this participant. As with others, remaining stoic was a priority and coping mechanism: "I have been in so many of those predicaments in my years as a social worker, you just come to expect it (laughter). It is part of the thick skin you need to acquire" (SWRUN17).

Weathering this storm led to an acceptance that the mistreatment was indeed occurring. This began with an element of disbelief and flooding emotions, of being shocked that mistreatment could occur within a family and within the home.

> There is always that sense of anger that one can do this. My whole career has been in geriatrics…it's my passion. There is a whole ray of emotions for me …sometimes I have those really sad conversations in my head. And sometimes I have those very angry conversations in my head. (SWU3)

Possibly due to the gravity of this confirmation, past negative case outcomes or encountered obstacles, participants hesitated to accept their suspicions. Eventually, the practitioner moved to the realization, becoming fully aware, that the mistreatment was occurring: "Sometimes we are a little leery to call it abuse but we know that it is…. We know that these things should never happen but yet it goes on every day" (GerU28). Acceptance was crucial to advancing to the next phase of questioning. Without remaining in this physical and psychological storm required to arrive at this acceptance, some cases were closed prematurely with doubt and regret later occurring.

Cognitive Uncertainty: Underlying Beliefs

Participants next began a phase of questioning, not necessarily aware that their conclusions were based on underlying beliefs. A first determination was made as to the intent of the mistreating caregiver. Malintent cases were the most challenging as caregivers refused formal intervention, fears for harm were greater, and the situation was at odds with the caring nature of these professions. One participant described malintent at an Alzheimer Day Program:

> He was rude, kind of push her out the door… it's hard because he picks her up, OK get in the car, time to go, grab all your shit, let's go…really brash and pushing them out the door…we are walking beside them with their walkers trying to make sure that they are ok… it is disheartening to see what they are going home to. (RtRUN7)

In other cases, where caregiver stress was high, cases were not necessarily deemed OAM: "Working with dementia, plus behaviors, we see a lot of care giver burnout…I don't think it's intentional" (NurRUN4). Participants seemed more comfortable managing these cases where interventions were welcomed.

Lastly, some intent remained unclear as participants questioned the caregiver's level of knowledge or if challenges with substance abuse, mental illness, or ineffective coping contributed to the mistreatment: "I didn't quite know … you struggle with: Can they appreciate that this isn't OK? Is it that they just don't care? Is it just apathy? Is this just how they have lived?" (NurU27).

Next, beliefs of vulnerability of dementia led to conclusions of mistreatment and to a perceived responsibility towards that older adult:

> It's upsetting, you know the client's at-risk and your instinct is to protect them… This man could not understand, he had a lot of confusion, had no insight into the police being called and why, and that the boys were taking advantage of him. (NurRN15)

However, when older adults with dementia exhibited disruptive behaviors, the latter served as a filter preventing one from naming the mistreatment: “One lady said: I would see my mom’s phone number and I just wanted to start screaming and swearing... That is not intentional abuse…” (SWRN16). However, participants were not at ease with this paradox which collided with assumptions of professional obligations.

In some instances, the diagnosis of dementia placed in question the veracity of the mistreatment. During a focus group, one police officer revealed:

> If we go (to the home), …the worst part is most police officers would err on the side of, ok, forgive me, ok grandma's crazy. We have someone saying yes, grandma, she's not all there, sorry she called 911. I have to be honest, and it's sad for me to say, that officer is going to leave. We have no ability to talk with grandma and really figure out, that you know what…? She does know what she's talking about and there is something bad happening to her. (FGIIRUN1)

For some, cognitive uncertainty resulted in triggering one’s risk breaking point, where one could no longer tolerate the risk to the older adult in the home. A sense of alarm overwhelmed some: “There are some nights that I will stay up nice and late and think … or wake up in panic mode” (GerRUN5). Some risks were specific: “especially when the bills aren’t being paid … there is some urgency, especially here because we have harsh winters. You can’t have people with no food and no power” (NurUN18). Many participants worried about the safety of older adults when they left the home: “if no one else is watching, what is going on” (NurU1). If the caregiver accepted long-term placement for the older adult, waiting on the crisis list could also be intolerable. Most frequently however, the mistreating caregiver refused placement.

On the other hand, some participants rationalized the older adult’s right to live at risk: “If the person who is being abused is aware of consequences, and they are fine with it…” (NurR10).

This narrative was exclusive to participants from one organization possibly reflecting that organizational culture. Lastly, rationalization occurred with participants who wanted more proof: "There have been concerns, but there is no proof, only conjectures and assumptions" (NurR24).

Emotional Upheaval: Values and Motives as Catalysts, but not enough

For those who 'stayed with' the case, an emotional upheaval motivated persistence. The value of dignity for the person with dementia propelled them to advocate for them as they reflected on their suffering:

> …what that means for the person? being told over and over, are you stupid? You must know the answer … The person starts to think well, maybe I am stupid…You're my son, you must know what is best, you are my husband, maybe I am stupid now. (RtRUN7)

When the older adult's cognitive status fluctuated, so too did their realization of the mistreatment, a difficult process to witness:

> She was very hurt by her son's actions and confused on how he could treat her this way and did not want to believe that he had done it. … when she started missing payments, she would get mad at herself for not remembering…dealing with all that emotion, and the upset and the crying and … I didn't feel prepared to deal with that. (RtUN23)

Some participants, also empathetic of the caregiver experience, were torn between two priorities: the well-being of the older adult with dementia and that of the mistreating caregiver. This was referred to as "that fine line…a difficult situation to be in" (NurRUN4). Knowledgeable of the high care demands of an older adult with dementia, one participant referred to these families as "traumatized by this disease" (SWRN16). However, caregiver empathy was always followed by an affirmation that mistreatment should never result. This truly left participants in a state of upheaval, of accepting the OAM they rejected: "… that intentional and unintentional abuse. You don't realize it…when you are in, neck deep in it. I find a lot of my care givers are just, floating there in the water" (NurRUN20).

Anger was most commonly elicited in these cases: “Angry… just not understanding how could you let your mother be in this living condition?” (NurUN22). However, emotions were not to be revealed to outsiders so as to not lose credibility: “they don't take it seriously, and you're scared to be portrayed as the emotional one that jumps the gun, you need to be really careful getting it across” (SWRN16).

Nevertheless, an experienced participant explained that emotions serve as an emotional catalyst: “…when you experience something at an emotional level, for me, it's kind of the drive behind pushing forth and trying to problem solve or rectify the problem” (FGIIRN3). This emotional drive was a characteristic of practitioners who persevered with cases; it served as a catalyst to persist with the case, described as “a fire in my belly” (RtUN19).

Despite this catalyst, participants described lacking power within the legal system:

> … there was neglect, and when we went to proceed with the hearing, we did not have enough information… the lawyers are there to prove we did something wrong, … they are hired to say, you prove to me why you think that they are at risk, or there is neglect. (NurU2)

As this focus group participant spoke, others nodded in agreement. Legal barriers were a common source of frustration: “how many times do we hit a wall? ...there's no legislation, there's no law… it's voluntary… there's always something that prevents us from really righting a wrong” (FGIIU5). To resolve this upheaval, legal and professional guidance was sought. Although very knowledgeable about OAM, in complex cases with dementia, they were torn between what could be legally done, what they should do, and the wrongness of the situation. “I think for someone (with dementia) we have an obligation to do something, an obligation, I don’t know if it’s a legal obligation. But we do have to help that person” (NurRN14).

Without legal guidance, decisions to intervene were considered what a ‘good professional’ should do. “Not really (not legal obligation), …as a nurse, I would feel the need to

say it. There is no, I don't really think there is, … it's really at our own discretion…" (NurR24). When asked about any organizational guidelines, most did not believe these existed: "I don't recall anything…more about my safety, because I do home visits" (NurRN14).

Lacking clear direction, decisions were based on values and beliefs about vulnerability, professional due diligence, and right and wrong: "… there is mistreatment… if police determine nothing is wrong, then we have done our due diligence. Not perhaps what we feel should happen…but documenting what we did, what we thought was appropriate, right?" (GerRUN5). This ambiguity left participants in an at-risk state themselves.

Inability to Resolve

This phase marked a realization that one had little power to eradicate the mistreatment within the home. Abandonment was described and one can hear the concepts of them and us: them, those who influence policy but are detached from the cases, and us, those for whom the cases are a daily reality:

> We're left to deal with these things on our own and it's shameful. Who do you turn to or where do you go asking for help? It's true, it's part of our reality…. there is nothing, you feel at a loss yourself, you are trying to help…and you can't. (FGIIRUN1)

For most, contacting police was futile and possibly dangerous: "my co-worker called the police and was told … there is not much we can do but take your report… if we got the police involved, was it going to be worse for him?" (NurR24). Participants from various disciplines echoed this lack of solutions: "There are no guidelines to tell me or other police officers how to proceed… it is up to the discretion of each professional to intervene or not" (FGIIRUN1).

Ultimately, participants searched for nonexistent solutions: "…to know what the rules are…and there aren't any". (FGIIRUN1) Despite having in-depth knowledge, participants were unable to stop the mistreatment: "there is lots of information but when it happens… These are things we can't fix" (FGIIR2).

Sharing with one's team decreased perceived abandonment by providing debriefing, support, reassurance and justification. Despite their professional experience and authority, when facing these cases, many were at a loss: "I always run it by somebody and then I'll know if I am being paranoid or overprotective or if it is really something …" (NurRN13). This notion of not overreacting was also present with supervisors: "My supervisor … when I say something is off, I can't identify what it is, because I don't do that too often, she recognizes that… she believes me" (NurUN11). However, although supportive, supervisors could not resolve the mistreatment: "very supportive but not somebody that I would draw anything from" (NurU27).

In the absence of a resolution, participants, especially those with more experience with OAM, became cautious mediators, acting a role in order to reach care objectives: "It's presented (as), we're here to help, as opposed to what are you doing that's making her scream? …accusing them would close the door" (FGIIRN3). The relationship with this dyad was compared to a careful dance: "You want the information, you want the relationship, so you try and do as much as you can by dancing around some of these things" (NurU1). This approach required time as their care objectives, of patient safety and appropriate care, were incongruent with the caregiver's. This participant describes her long-term objective: "At first, I thought it was an educational thing…she continued to lose weight… then, some patterns were showing… weeks and months. My goal was to get her out of there" (NurU27).

The relationship with the mistreating caregiver became one of supervision. Formal practitioners became the "eyes" in the home, ready to sound the alarm if the mistreatment escalated: "we try to tiptoe around how to keep this person safe, keep services in so at least somebody is watching that nothing huge is happening…." (FGIIR2).

Despite the supervision in the home, participants realized they were not preventing the mistreatment. Reflecting on their lack of professional agency was painful. An interesting paradox

was noted with a participant, who although describing her case described in the past tense, spoke of her feelings in the present tense:

> That was one of the worse cases that I worked with. It has actually stopped me from sleeping some nights. And the son, I could have advocated for more care giver support, but he of course didn't want to have more eyes in the house. Awful, I feel awful. I feel thankful that we actually had outsiders going in there and kind of keeping an eye on it. But it makes me really sad. (SWRUN17)

Northern and rural participants faced additional challenges and described a perceived responsibility towards their cases despite precarious winter driving and large geographical areas, as much as five hours across: "…you can't drive there, you can only take a train to [closest city] and then you fly .... I don't have the capacity. But I do carry a caseload" (GerRUN5). In some regions, participants took turns covering for vacant caseloads in a five-hour region by telephone. One participant described disregarding one in-home practitioner's concerns of mistreatment as she was unable to speak with the older adult on the telephone. Doubt about this case persisted in her mind.

Isolation was described: "I'm solo here… there is nobody else" (GerRUN5). Being alone in a satellite office increased perceived responsibility: "Unfortunately, lots of us don't have the team…that's our reality" (FGIIRUN1). In addition, a lack of local supervisory support was described.

Their scope of practice was also enlarged: "You have to be Jill-of-all-trades" (FGIIR2). Professional limits were blurred. One participant with experience in OAM received police in her home. A police officer secured an apartment to free a couple from their mistreating son. This participant explains her interventions beyond her nursing scope with a case of severe financial mistreatment by a son: "We were going to the food banks and picking her up food and supplies… going to the humane society and picking her up dog food…accessed the community

trust so her power wouldn't get shut off…" (NurUN18).

The Double-edged Sword of Self-reflection

"Being with" their past cases and describing events and outcomes were challenging, awakening painful recollections. A common case occurrence was the crisis, which, although harmful, was necessary to end the mistreatment. This crisis resulted in hospitalization, long-term care placement, or even death. Descriptions of these crises were factual: "She ended up going into a nursing home…. and passed away. Medically, she declined enough that an ambulance was called…and that is usually what happens" (NurU26); "she was frequently admitted with urinary tract infections…last time she died" (NurRN6).

The crisis could not be prevented as risks did not warrant legal intervention and those outside the home did not recognize the danger. However, the crisis forced acknowledgment of the OAM outside the home:

> We had already brought this up a year and a half prior … but we just kind of wait for the ball to drop unfortunately with a lot of these cases, we're waiting for something severe to happen … and this is going to sound terrible, but it's almost better for us because we have more options. (FGIIRUN1)

There were psychological costs of welcoming this crisis:

> You're seeing that they're just failing, they're losing weight …you're waiting …she finally fell, broke her hip, ended up in hospital, went right to long-term care. But we had to have the crisis. We watched her silently suffer but nobody could be charged. She wasn't deemed incapable but she had dementia. (FGIIRN3)

When long-term care placement did occur, some professional agency resulted from providing safety. This participant describes her emotion the day a husband and wife, both with dementia and mistreated by their son, were placed:

> I was so relieved, it was one of the happiest days…Because I knew that they were OK, they are in a safe environment… it all ended up being a success story in the end. Do they always? not so much… (SWRUN17)

Participants knew that mistreating caregivers were not held accountable, but accepted they could not control that societal injustice. Their priorities were health, care, and quality of life, not the law which was outside of their realm:

> Can you change it? Are they going to be prosecuted for this? Well maybe we don't have to worry so much about that… with this lady, nobody is going to do time because of theft, neglect, but she now has appropriate care and comfort… (NurU27)

Lacking guidance, solutions, and waiting for a crisis, a personal moral exercise ensued about one's personal responsibility. Most participants believed it was their duty to intervene and this unwavering sense of responsibility towards the mistreated older adult with dementia provided personal strength: "I'm doing what I think is right…being a voice when there is no voice anymore…the more I reflect on all of my experiences…the braver I become to advocate and protect" (SWRUN17).

Not all felt this personal sense of responsibility, reasoning that this was not within their scope nor organizational mandate. Actions sometimes felt quite enormous and lead to questioning one's responsibility. This participant explains that it would be easier to disregard the mistreatment: "…accountability … it would have been easy for me to not have seen any of that and to let it (go)" (NurU27).

Reflection and sharing resulted in profound realizations. Many had suspected OAM but needed confirmation of their experiences. As participants reflected, worry, doubt, and regret surfaced. Worry, about those discharged from care, was common:

> I often wonder about her, because we don't have access to her now… she goes to the day program. Before I closed the file, I wanted to make sure that this part was done…I felt that someone was kind of watching…other than the family. (NurRN6)

Others expressed doubt about their interventions, struggling with what they had witnessed and what they could have done:

> These cases … they do stay with you, they don't go away. Unfortunately, you always wonder, could I have done something differently? … the worst thing is to think I should have done this differently…and perhaps there was a different outcome because of it. (SWU3)

Lastly, some expressed regret, either of not believing an older adult or in-home practitioner report, of not being aggressive enough in their response, or of not trusting their intuition:

> … ask questions. I think if I had, if she had told me, I would have been maybe more aggressive, and try to do something. And I always feel bad about that because she didn't trust me enough to say anything or just…. I don't find I did help her, because I couldn't, I didn't really change very much in her life. (NurRN6)

Overwhelmingly, a lack of control was described. Only partial professional agency could be achieved by trusting one's intuition, providing in home services, supervising to prevent escalation, and long-term care placement. These interventions were considered meaningful:

> We were ensuring that consistent service…it (home care visits), gave him a little bit of confidence that somebody was going to come in every day. And so, that is all we could do really. I feel like, as long as we stay client centered, that is meaningful. (NurR24)

In most cases, positive outcomes were not achievable: "Frustrated and discouraged…I knew we didn't have many options for her…the victims continue to suffer" (GerRUN5). Participants spoke of lacking power to control the case and having to accept that they could not

fulfill their perceived professional duty to protect. When unable to stop the mistreatment, participants did not feel they had acted in a professionally meaningful way: “it is hard to feel like you are making a positive difference or contribution when I can’t change that part” (NurRUN20). These cases were morally distressing for some:

> Deeply saddened doesn't even cover it, because I know, that at the end of the day, there's not a whole lot more I can do for them. I don't even know how to describe it, it's… it's just a reality. (FGIIU5)

Discussion

This study aimed to understand practitioner’s experiences with OAM in rural and northern contexts. Analysis of the dataset focused on providers’ underlying beliefs, understandings and motives with OAM and dementia and their perceptions of professional agency in these cases. “The experience” was described as a storm where cognitive uncertainty and emotional upheaval reigned and where practitioners were unable to resolve the OAM. Reflecting on these cases was both a positive and challenging experience and facilitated an understanding of a need for empowerment in these cases.

Challenge of the Storm

Encountering cases of OAM and dementia within the home was explained as a multifaceted experience. Initially bombarded by a storm, practitioners lost their professional grounding. This storm, as opposed to the prevailing ideology in the literature of professional authority and composure, is identified when analyzing data dialectically, therefore, what is versus what should be (Fontana, 2004). Although fear for the older adult with dementia prevailed, reflection on these cases also permitted the realization of one’s fear-for-self. Few studies have addressed this notion of fear (Beaulieu & Leclerc, 2006; Omote et al., 2007; Sandmoe & Kirkevold, 2011). To provide grounding, those with more exposure learned to trust their intuitive alarm, a notion identified by others (Bergeron, 1999; Saveman et al., 1993). When

this intuition was not trusted as factual knowledge, cases were potentially disregarded. However, as explained by Spratt & Houston (1999), in their study with child protection workers, intuition, unlike traditional factual knowledge favored in society, represents a moral-practical knowledge which has the potential to address human problems.

Remaining in this storm was challenging. Anetzberger (2005) found that in cases of OAM, practitioners may not see the OAM in an attempt to protect themselves from its assault. Similarly, not all participants remained in the storm, perhaps in an attempt to protect themselves, not seeing the mistreatment, and closing files. Those who remained in the storm worked through a process of acceptance that OAM actually occurred within families, a notion in opposition to the societal norm of caring for one's loved one. Spratt & Houston (1999) comparably describe this professional challenge when practitioners encountered child abuse within families. Those who were able to see the OAM, recognize their fears, and not disregard the intuitive alarm, remained in the storm. Beliefs of danger for the older adult and the need for protection equated to a personal responsibility beyond that of their professional duty as a health or social services practitioner. These participants were clear on their sense of social responsibility and commitment to others, notions that Freire (1972) identifies as prerequisites to critical consciousness, the acquisition of critical knowledge about one's reality (Fontana, 2004). Finally, realization was achieved: they became fully aware, accepting the wrong, an acceptance that motivated them to proceed to the phase of questioning.

Questionning

Exposure to mistreatment and dementia initiated a cognitive uncertainty, a process of questioning if the specifics of the case indeed confirmed OAM. Using dialectic reasoning (Fontana, 2004), participants realized that cases of mistreatment were not automatically determined: factors such as intent of caregiver, vulnerability, and form of mistreatment lead to a conclusion. This finding was also noted by Lithwick and colleagues (1999) who concluded that

contextual factors such as cognitive impairment or unclear intent influenced practitioner thinking in OAM cases. In the present study, specific to dementia care, caregiver stress situations were less apt to be named mistreatment. Even in discussions of clear malintent, many felt the need to rule out stress perhaps due to beliefs about what should be, and realizations of their incapacity to eliminate malintent within the home. Persistence, time, and a willingness to 'stay with' the case were essential, restrictions noted by other community care practitioners (Beaulieu & Leclerc, 2006). Otherwise, the cognitive uncertainty could result in case closure or simply not getting involved, consequences noted in an OAM study by Erlingsson and colleagues (2006). Dialogue during focus groups permitted the reflection upon the societal taboo of this disease which complicated the presentation of the mistreatment, influenced beliefs and consequently, the actions taken.

One's internal trigger clearly marked a point of no return for most, a conviction that risks could not be ignored. This notion of risk or "dangerousness" of a situation influencing intervention has been previously reported (Beaulieu & Leclerc, 2006, p. 171; Mixson, 1995). However, some participants, all from one particular organization, rationalized the situation as an older adult's right to live at risk, a dangerous ideology where lack of interventions was justified. Even when probed about incapacity due to dementia, the rhetoric of right to live at risk persisted, in an automatic fashion. This could be attributed to the prevailing ideology of right to live at risk in provincial policy documents (Sinha et al., 2016) and the inherent risks in the Canadian home care context (Ceci & Purkis, 2009). Habermas (1976) explains how structures and dominant ideology can influence beliefs resulting in infected discourse. When this ideology of risk infected participants' dialogue, their cases were most frequently not pursued into the next phase. During data collection, dialogue and critical self-reflection were challenged due to discomfort sharing interventions or lack thereof, challenges identified by Sumner (2010a). Ultimately, some cases of

evident mistreatment were dismissed by these participants despite evidence as the ideology of permissible risk was stronger than this critical internal trigger.

Emotional Catalyst

Emotional upheaval experienced by practitioners is rarely discussed in the literature although Beaulieu & Leclerc (2006) described that their practitioners shared their worries, malaise, and limited power in mistreatment cases. However, as dementia is an exclusion criterion in most studies, emotions experienced in cases with this particular subset of mistreated older adults are unknown. As also described by Swedish community nurses (Saveman et al., 1993), participants tried to understand the experience of older adults by imagining their thoughts and feelings when being mistreated by their caregiver. This is by no means a lack of objectivity but is rather an attempt to understand the "subjective world of dementia" (Kitwood, 1997a, p. 13), a "getting close" which is encouraged in order to meet psychological needs of attachment, inclusion, identity and comfort (Kitwood, 1997a, p. 17). These needs must be met in order to maintain personhood, defined as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" (Kitwood, 1997b, p. 8). Therefore, witnessing mistreatment by a family caregiver, who should be pivotal to maintaining personhood, resulted in an emotional upheaval for practitioners. However, in addition, these practitioners were torn between the two members of the dyad, describing empathetic understanding of the caregiver's burden. They therefore had to accept the unacceptable, or as Fontana (2004) would describe, find themselves in a dialectical tenuous position. This empathetic consideration for the caregiver burden experience was previously identified with practitioners in Quebec, Japan and Sweden (Beaulieu & Leclerc, 2006; Erlingsson et al., 2012).

Nevertheless, it was specifically intuitive and moral knowledge that served as the catalysts propelling practitioners to persist despite the barriers encountered in these cases. They

felt an obligation to act as a 'good' professional, even without legal/professional basis. These participants relied on their experiential intuition, questioned policies, and advocated for older adults, demonstrating Habermas' (1976) concept of moral consciousness. Ethical principles were used based on beliefs and values of what should occur, a complex struggle with OAM, as noted in the literature (Beaulieu & Leclerc, 2006; Killick & Taylor, 2009). Despite this strength, a lack of solutions created vulnerability as actions were left up to one's discretion. Reflection helped them to disentangle these perceived responsibilities through a process of dialogue and justification of actions.

Impossible Resolution

The lack of guidance and solutions led to feelings of disappointment, lack of power, and distress, findings previously reported with OAM cases (Beaulieu & Leclerc, 2006; Saveman et al., 1996) when "exposure is perceived as vulnerability" (Winterstein, 2012, p. 58). Although knowledge about an issue would expectedly lead to competence, this did not occur with these OAM cases where there were no solutions to be found. Instead, knowledge and experience lead to a higher critical and moral consciousness, competences that develop when realization is reached (Freire, 1972; Habermas, 1976). Therefore, practitioners with these competences had more questions than answers.

Exposing hidden power imbalances is a key function of CST (Ruangjiratain & Kendall, 1998). Power of the mistreating caregiver over not only the older adult with dementia, but also over the formal practitioner, forced the latter to play a role, giving the impression that the caregiver still controlled the situation. Similarly, Omote and colleagues (2007) described a process of "ingratiation" where practitioners pretended to agree and act kindly towards the mistreating caregiver. This action was meant to protect the victim, a previous finding with APS workers (Bergeron, 1999). This façade was built on their beliefs, values, and motives of quality of care and safety for the older adult.

Rural and northern participants were further limited by unrealistic coverage of large geographical areas, a larger scope of practice, a blurring of professional limits, and lack of supports. These limitations increased their burden of perceived professional and personal responsibility to eradicate the OAM. The ideology of resilience in rural and northern context creates the impression that one can overcome adversity in these environments. This is a dangerous notion however which can absolve government of their responsibilities in rural and northern areas further compounding the vulnerability of practitioners who feel they are alone to find solutions, findings previously touched upon in OAM studies (Beaulieu & Leclerc, 2006; Vandsburger et al., 2012). Team structure and resources, found lacking in the rural regions of this study, have previously been identified as negatively influencing decision-making in OAM cases (Killick & Taylor, 2009). Team support has been described as essential by American APS workers in contexts where adult protective legislation exists (Bergeron, 1999). It is also somewhat similar to the brainstorming, support and possible case referral formal practitioners obtained from adult protective workers in Nova Scotia, Canada where adult protective legislation does exist (Harbison et al., 2005). However, it greatly differs from all studies in that sharing in this study was not about reporting to an entity responsible for OAM or of seeking solutions which are nonexistent in this province.

Self-reflection

Self-reflection was validating for many. Participants demonstrated "considerateness" of each other as they were sincere and negotiated a mutual understanding (Fulton, 1997; Sumner, 2010b). Nevertheless, the process also revealed feelings of failure, guilt or ineffectiveness. There was guilt in wanting a crisis and this dialectical acknowledgment was distressing to participants (Fontana, 2004). The concept of welcomed crisis has not been previously addressed in the literature, although the notion of facing an OAM crisis requiring protective intervention has been highlighted with American adult protective workers (Dayton, 2005). One such crisis, placement

in long term care to ensure safety, was in stark opposition to the current ideology of safe and better aging in place at home within the existing home care system (Sinha et al., 2016). Placement, as a successful outcome in OAM cases, has been reported elsewhere (Lithwick et al., 1999).

For many, sharing lead to acquiring critical knowledge of their mistreatment cases which, until having had this opportunity, had not been recognized. This possibly occurred due to heavy caseloads, not having time to reflect on their practice, or the normalization of risk within the structure of home care (Ceci & Purkis, 2009). Increasing complexity of home care recipients, extended life expectancies with comorbidities, ageism as a socially dominant ideology, expectations of family caregiving, and beliefs about dementia are all factors that can lead to this normalization preventing them from "seeing" their cases as they become "routinized to human suffering" (Sumner, 2010a, p. E25).

This powerful realization also occurred for the first author, during data collection and analysis of transcripts. As participants shared their cases, certain aspects resonated for reasons not immediately recognized. Memoing was instrumental in preventing contamination of the data by prior personal experiences with OAM (Morse, 2015).

Practitioners could not meet their perceived professional duty to protect the older adult. This is similar to Killick & Taylor's (2009) finding of inability to successfully protect the mistreated older adult and Lithwick and colleagues' (1999) finding of the need to accept harm reduction measures versus the elimination of mistreatment. For many, these cases were morally distressing, an experience previously described with nurses prevented from protecting their at-risk patients within powerful societal structures (Corley, 2002). This has also been identified by American Adult Protective services workers (Bergeron, 1999; Dong, 2012). Self-reflection on their past cases, occurring during interviews, reflective journals, and focus group discussions, brought many to the realization of their own vulnerability as they lacked the control to change

the older adult's suffering. Although somber, the new understandings achieved in this Understanding phase of the study were promising as the basis for change in the Empowerment phase (Bennett, Bergin, & Wells, 2016).

Conclusions and Limitations

This study revealed findings not previously reported in the literature including: the emotions and moral knowledge which serve as a catalyst propelling practitioners to persevere with their OAM cases, the stoic professional armour they doned to protect the older adult and their professional image, their feelings of abandonment when managing cases without adequate systemic support, the guilt of waiting for and wanting the crisis that would effectively bring the OAM outside of the hidden home context where they were powerless to stop it, and the doubt and regret that remained with them from past cases. However, there were some study limitations.

Recruitment and retention of interview and focus group participants from some of the targeted organizations was challenging. This was firstly experienced at an administrative level where concerns about human resource burden resulting from participation and the revelation of internal policies and procedures on OAM were expressed.

Once the recruitment strategy was modified to address these concerns, recruitment in both rural and urban areas was challenged by limited human resources and heavy caseloads. All attempts to make interview, journaling, and focus group participation as effortless, comfortable and meaningful as possible were made, and as a result, a sufficient number of participants was reached to achieve saturation.

Five participants chose not to continue participating beyond the interview, citing heavy workloads. When reviewing interview transcripts however, their past cases of OAM and dementia were very challenging and it could be that self-reflection was not considered personally helpful. Also, due to a strong ideology of the older adult's right to live at risk and service limits

within one organization, long-standing conflicts with other organizations may have diminished their interest to join others in a focus group.

Expanding recruitment to other community organizations, to compensate for these recruitment and retention challenges as well as snowball sampling resulted in a heterogeneous final sample. Learning about this experience from diverse disciplines undoubtedly provided an unexpected depth and breadth of knowledge.

Findings from this study are different from many assumptions in the literature: that formal practitioners can remain psychologically, physically, cognitively, and emotionally untouched by these cases; that they ought to, should, and must intervene in cases of OAM; that they lack knowledge; that they have the power to intervene; that all older adults can be empowered in these cases; and that all older adults can be safe aging at home. This study exposes the complexity of these cases when the older adult with dementia is mistreated by their informal caregiver. It also illuminates the multifaceted experience lived by formal practitioners and the resulting lack of professional agency when legal and professional guidance are lacking. Lastly, it begins to address the research-policy-practice gaps in this field where decisions are not made by those who experience this reality and who are best positioned to advocate for the mistreated older adults in their care.

The power of reflection can be positive as it facilitated “seeing” one’s cases, recognizing how multifaceted this experience is, and learning how others are experiencing a similar lack of professional agency. It can also be negative as cases were relived, accompanied by worry, doubt, and regret. The CST lens and methodology, using methods permitting dialogue, reflection, and dialectical and critical reasoning, facilitated this knowledge development.

Further research is required into the experience of front-line practitioners with OAM, dementia, and the informal caregiver within the home context. Although this inquiry has exposed factors contributing to an increased burden of perceived responsibility, isolation and expanded

scope of practice for rural and northern practitioners in OAM cases, additional studies need to revisit this experience within the rural and northern context. We need to know more about the factors that would support intervention in these complex and emotionally charged cases, and those that impede professional agency. On a policy basis, we need to acknowledge the necessity to better support practitioners who feel abandoned within the current system, want to intervene prior to a crisis, and with whom the doubt and possible regret of past OAM cases remain. For the field of OAM to progress, we must permit practice to inform research and policy.

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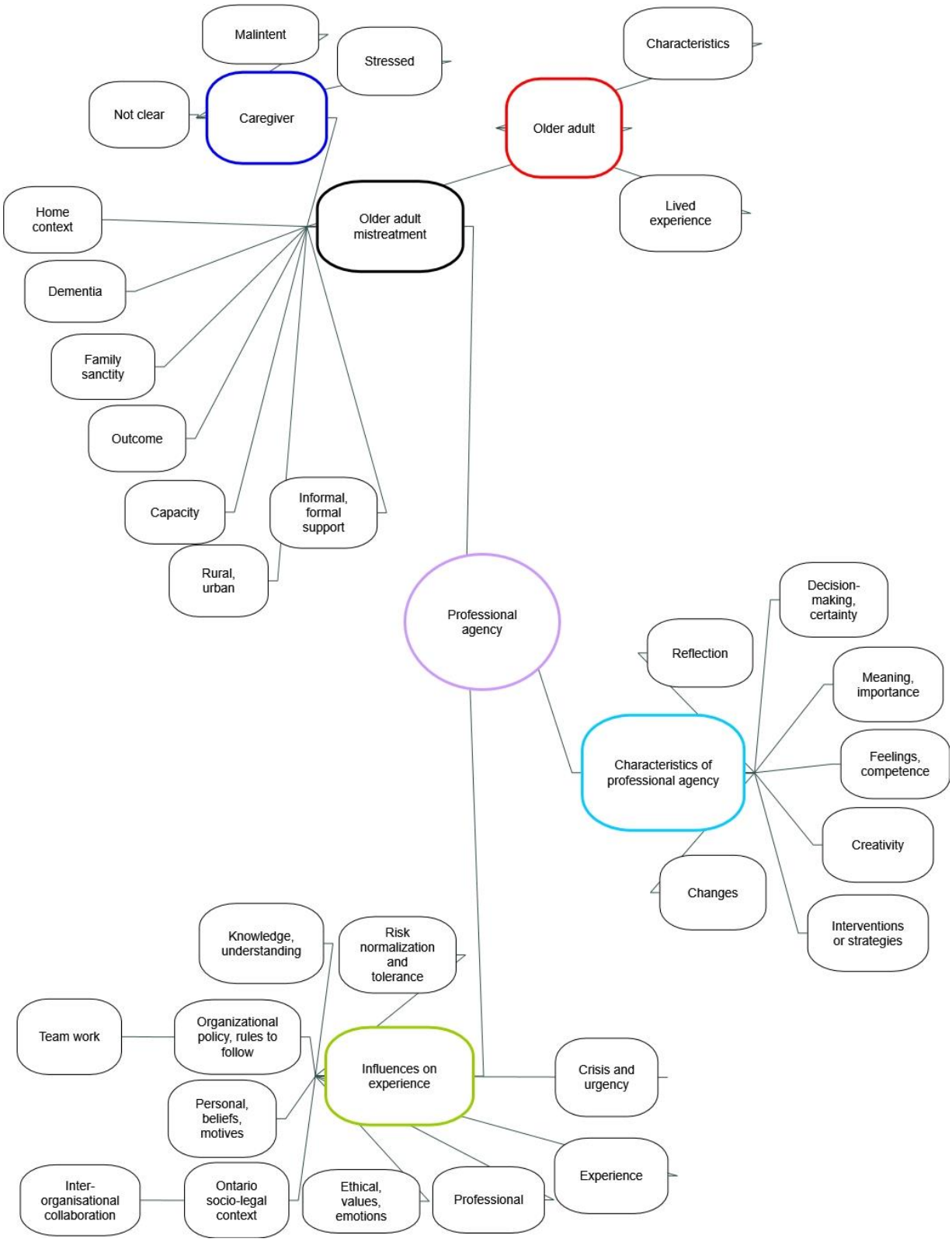
Table 1. Interview participants

Identifier	Rural/Urban/Northern or combination	Discipline
NurU1	Urban	Nursing
NurU2	Urban	Nursing
SWU3	Urban	Social work
NurRUN4	Rural/Urban/Northern	Nursing
GerRUN5	Rural/Urban/Northern	Gerontology
NurRN6	Rural/Northern	Nursing
RtRUN7	Rural/Urban/Northern	Recreational therapy
NurUN8	Urban/Northern	Nursing
GerR9	Rural	Gerontology
NurR10	Rural	Nursing
NurUN11	Urban/Northern	Nursing
NurUN12	Urban/Northern	Nursing
NurRN13	Rural/Northern	Nursing
NurRN14	Rural/Northern	Nursing
NurRN15	Rural/Northern	Nursing
SWRN16	Rural/Northern	Social work
SWRUN17	Rural/Urban/Northern	Social work
NurUN18	Urban/Northern	Nursing
RtUN19	Urban/Northern	Recreational therapy
NurRUN20	Rural/Urban/Northern	Nursing
SWU21	Urban	Psychology
NurUN22	Urban/Northern	Nursing
RtUN23	Urban/Northern	Recreational therapy
NurR24	Rural	Nursing
SWRUN25	Rural/Urban/Northern	Social work
NurU26	Urban	Nursing
NurU27	Urban	Nursing
GerU28	Urban	Gerontology

Table 2. Inquiry Focus Groups

Identifier	Rural/Urban/Northern or combination	*n*=29	Years of experience	Disciplines represented
FGIIRUN1	Rural/Urban/Northern	9	6-22	Nursing, Criminology, Psychogeriatric, Domestic abuse, Social work, Gerontology
FGIIR2	Rural	4	10-35	Nursing, Social work, Gerontology, Domestic abuse
FGIIRN3	Rural/Northern	6	5-31	Criminology, Gerontology, Nursing, Business administration
FGIIU4	Urban	3	10-20	Social work, Criminology
FGIIU5	Urban	7	1-42	Social work, Health, Gerontology, Nursing, Corrections

Appendix 1-Coding framework: The experience



Chapter 3: Older adult mistreatment, dementia, and the home: Practitioner oppression in Northeastern Ontario, Canada

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The risk of older adult mistreatment [OAM], occurring within the home context and perpetrated by a family caregiver, is a cause of great concern in Canada as well as internationally (Brozowski & Hall, 2004; Lowenstein, 2010). Although reprehensible by society, OAM perpetrated by a family caregiver occurs in 85-90% of cases (Amstadter et al., 2011; Choi & Mayer, 2000; National Center on Elder Abuse, 1998). The presence of dementia further increases the risk of OAM as demonstrated by alarmingly high prevalence rates with this group of older adults (Alzheimer Society of Canada, 2010a; Yan & Kwok, 2011). Given the projected rise of dementia in Canada, and the shift towards aging at home, focus on OAM with this sub-set of older adults is imperative (Alzheimer Society of Canada, 2010b; Fang & Yan, 2018). In the province of Ontario, Canada, the focus of this study, there is no adult protective legislation or infrastructure specific to OAM occurring within the home context (Department of Justice Canada, 2015). Furthermore, in the specific region for this study, Northeastern Ontario, population aging, health disparities and reduced health care access represent further indications for concern (Health Quality Ontario, 2017). Given these risks, the experience of health care and social services practitioners who have access to these mistreated older adults in the home must be understood as they strive to provide quality care within the influences of home health, social services, societal ideologies, and legislative and geographical contexts. However, we know little of this experience and how it is influenced by these contexts (Killick & Taylor, 2009; Omote, Saeki, & Sakai, 2007). This paper presents findings from a critical inquiry conducted with

practitioners from urban and rural Northeastern Ontario on the influences of health-care, socio-political and geographical contexts on professional experience with OAM and dementia cases.

Background

Older adult mistreatment [OAM], commonly known as elder abuse, is defined as "actions and/or behaviours, or lack (thereof), that cause harm or risk of harm within a trusting relationship" (McDonald, 2015, p. 6). In a review of international prevalence studies of OAM occurring in the home, McDonald (2015) summarized rates as ranging from 0.8-36.2%. However, international studies on OAM in the home report a dramatic increase in prevalence rates when the older adult had dementia: 34.9% (Sasaki et al., 2007); 47.3% (Wiglesworth et al., 2010); 52% (Cooney, Howard, & Lawlor, 2006); and 62.3% (Yan & Kwok, 2011). Although rates of OAM in long-term care institutions also range from 39.7% (Germany) (Rabold & Goergen, 2013) to 63.8% (United States) (Page, Conner, Prokhorov, Fang, & Post, 2009), the current shift towards aging in place in one's home necessitates study of this context.

Numerous studies have concluded that in Canada, one in five older adults receiving home care has a diagnosis of dementia (Canadian Institute for Health Information [CIHI], 2010a), and approximately 80% of homecare is provided by a family caregiver (CIHI, 2010b). As well, the projected rising prevalence of dementia and informal caregiving in Canada over the next 30 years (Alzheimer Society of Canada, 2010b) will create an excessive reliance on the family caregiver, a problematic situation as increased risks inherent to the older adult with dementia/caregiver dyad are contributors to OAM (for thorough report, see Alzheimer Society of Canada, 2010a). Furthermore, the home care system in Ontario has been characterized by fiscal constraints, strict eligibility criteria, and limited service allotments (Yakerson, 2019). As care shifts from institutional care to home care, rates of dementia rise, and more older adults with dementia remain at home (Fang & Yan, 2018), studying the home context of care is imperative.

Within Ontario, protective legislation only exists for victims of intimate partner violence, at-risk adults with developmental disabilities (since birth), older adults in long-term and residential care institutions, and for children (Government of Ontario, 2018a, 2018b, 2018c, 2018d; 2019a). Therefore, in Ontario, there is neither legislation nor infrastructure specific to OAM occurring in the home although this does exist in other Canadian provinces (Canadian Centre for Elder Law [CCEL], (2011); Department of Justice Canada, 2015; Hall, 2009).

In addition, few studies have focused on the geographical context, specifically OAM occurring in urban or rural regions. Few Canadian studies have explored the rural context: Harbison, Coughlan, Karbanow, & VanderPlaat (2005) studied OAM interventions within a context of adult protective legislation; MacKay-Barr & Csiernik (2012), and Weeks, Richards, Nilsson, Kozma, and Bryanton (2005) explored characteristics of the rural dyad; Brozoswki & Hall (2004) discovered that rural residency increased OAM risk throughout Canada; while Stones & Bédard (2002) identified rural attitudinal differences on OAM. Recently, Statistics Canada (December, 2018) concluded that rates of family violence against older adults are rising, especially in rural Canada. Thus, inquiry is needed to understand the influences of home health and social services, socio-legal, and geographical contexts on the practitioner experience of professional agency, one's ability to influence case outcomes (Frie, 2011).. Specifically, this paper draws on qualitative data with practitioners in a region where no adult protective legislation exists to explore how prevailing ideologies and dominant structures influence the experience of professional agency and whether practitioners perceive a need to improve their agency.

Methods

This was a two-phase study with phase one being primarily concerned with understanding an experience within the larger context of care, and phase two focused on

empowerment to act on the findings. However, data generated from both phases are combined and considered in this paper.

Theoretical Underpinnings

Based on historical realism, critical social theory [CST] (Habermas, 1971, 1976) permits the reflection upon, exposure and challenge of oppressive ideologies and social structures that are upheld by those in power (Xiao, Kelton, & Paterson, 2012) and that shape beliefs and values about the world (Lincoln, Lynham, & Guba, 2011).

As sources of oppression may be subtle, CST research requires digging beneath surface appearances (Fontana, 2004) and sits within a contextualist paradigm (Maggs-Rapport, 2001). Thus, the subjective individual experience of professional agency with cases of OAM cannot be extracted from the factual health, geographical, and socio-political systems (Norris, Fancey, Power, & Ross, 2013).

Reflection and critique, foundational to CST, must occur for both the researcher and the research subjects (Fontana, 2004). As it cannot be neutral, the CST researcher begins by exposing their personal, political, and socially critical theoretical positioning (Grant & Giddings, 2002). The first author has previously shared self-reflections on this experience, a process which continued throughout this study (Lindenbach, Larocque, Morgan, & Jacklin, in preparation).

By exposing unequal power relationships within contexts, participants gain powerful critical knowledge necessary to change their oppressive situations (Fontana, 2004). CST is closely tied to the work of Freire (1972) on awakening critical consciousness of hidden power imbalances required to understand and transform a current reality.

Methodology

Three fundamental processes contributed to this critical methodology: reflection, dialogue, and dialectic reasoning (Fontana, 2004). Interviews and journals facilitated participant self-reflection on their experiences (Habermas, 1971). To respect the democratic quality of

collaborative critical knowledge development, dialogue was next used in focus groups (Comstock, 1982; Fontana, 2004; Habermas, 1976). Finally, dialectic reasoning, a process of using questions to examine statements logically to identify societal contradictions and challenge assumptions about ideology, was applied (Sumner, 2010a). Truths progressively discovered through interviews and journals were presented during focus groups, where critical dialectic discussions challenged the status quo and analyzed how experienced power imbalances were sources of oppression (Fontana, 2004; Freire, 1972).

Ethical approval was obtained from the Laurentian University Research Ethics Board and the ethics committees of all participating organizations. The names of these organizations are not disclosed to protect participant confidentiality as those in small rural regions might be the sole representative of an organization, and to address the concerns of some organizations that policies regarding OAM would be revealed and critiqued.

Sampling

Purposive sampling was used to seek practitioners of health and social care, community services, and police officers who had experienced a past case of OAM and dementia within the home by a caregiver. Practitioners from five Northeastern Ontario geographical regions were invited to participate. The map of this region is included in Appendix 1. Rurality was defined using the Rural Small-Town definition: "towns or municipalities outside the commuting zone of larger urban centres (with 10,000 or more population)" (du Plessis, Beshiri, Bollman, & Clemenson, 2001). Applying this definition to data from the 2011 Canadian Census, regions were classified as either rural or urban. Next, although all areas of Northeastern Ontario are considered "northern" (Health Quality Ontario, 2017), for the purpose of this study, regions were only considered "northern" if winter closures of Trans-Canadian highways prevented access to these communities. Practitioners stressed the importance of this factor in their ability to care for the older adults/caregivers in their homes.

Fifty-one practitioners participated in Phases I and II (some participated in both phases). Tables 1 and 2 describe the interview and inquiry focus groups sample respectively, assigning a participant identifier to refer to the findings. Backgrounds were varied and participants had worked primarily with older adults during one to 42 years of their careers. In total, 23 Ontario health and social services organizations are included.

Data collection for Phase 1 was initiated in October 2016 and lasted through March 2017. In-depth semi-structured interviews lasting 1-1.5 hours were completed with practitioners providing services directly to the home. A reflective journal followed to further develop an interpretive understanding of participants' beliefs, values, and motives in cases of OAM and dementia. Next, practitioners primarily providing supports from within the community participated in inquiry focus groups. The focus group method was chosen to encourage participant dialogue, reflection, and critique of individual truths. Therefore, focus group discussions aimed to learn how groups made sense of each other's actions within the current contextual structures.

Data collection for Phase II was conducted in April-May 2017. The action phase, bringing together interview participants who provided insights about OAM within the home and inquiry focus groups participants who offered support outside of the home, offered participants an opportunity to discuss the findings from all 5 geographical regions, critique the dominant ideologies and structures preventing them from having professional agency in their cases, learn that they could be agents of change, and decide on a plan of action to change these oppressive structures.

Findings related to the experience of practitioners with OAM and dementia, as well as the action projects they chose to undertake, have been reported elsewhere (Lindenbach et al., in preparation; Lindenbach, Larocque, Morgan, & Jacklin, in preparation).

Theoretical Thematic Analysis

Theory-led thematic analysis (Braun & Clarke, 2006) guided the iterative analysis throughout all interviews, reflective journals and focus groups, as collective meanings shared by all participants were sought. Field notes were crucial to retain all data throughout the eight months of data collection (Morse & Richards, 2002). After data immersion, initial coding frameworks were formed based on the research sub-questions, the theoretical framework, and the primary researcher's analytic preconceptions. Using NVivo 11, data extracts were organized into these coding frameworks which were continuously revised throughout data analysis, resulting in three final coding frameworks on three key themes: the experience of professional agency, the influence of contexts, and the need for empowerment. The coding framework focused in this paper, contextual influences, is provided in Appendix 2. Next, the analysis deepened to a latent level, where repeated patterns across the data were noted. As a result, sub-themes were identified for each key theme of experience, contextual influences, and need for empowerment. This paper draws on the data from the two-phase study but presents the data filtered through the key theme of the contextual influences on the experience.

Results

Five sub-themes were identified (Figure 1): the privileged burden of seeing behind closed doors; domestic problem within societal context; interprofessional imperative with impossible problem; history of stagnation, losses, and systems failure; and legislative complexity and oppression. Sub-themes are depicted as contexts, situated within, and therefore impacted by larger contexts.

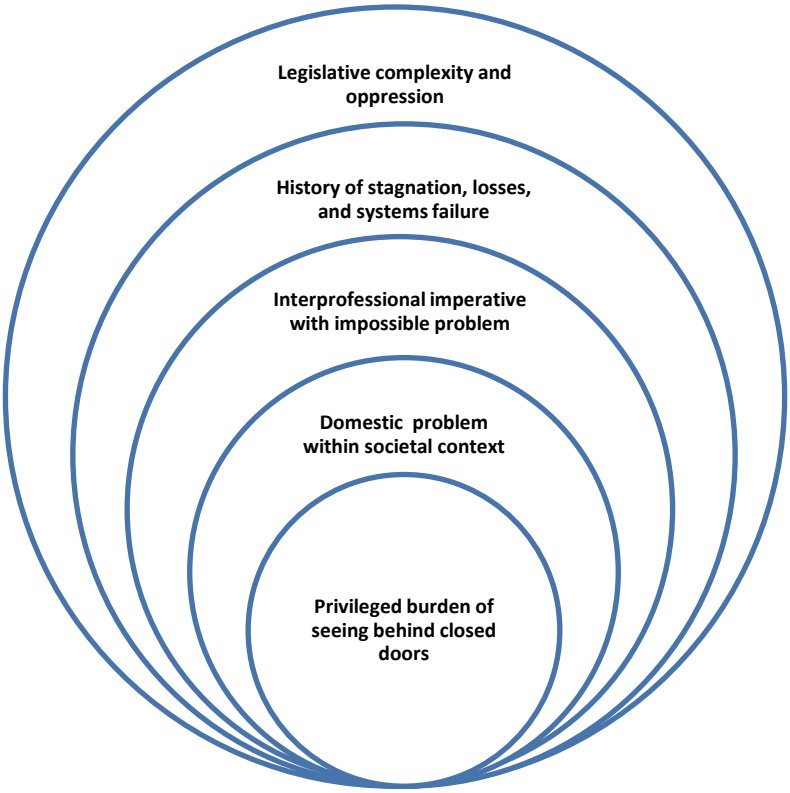

Figure 1: Key theme: Contextual influences

The Privileged Burden of Seeing Behind Closed Doors

Findings revealed the privilege of accessing the home context where practitioners could see a more complete picture:

> We would meet here (in the health center) with the physician and the nurse practitioner and they had no concerns. …That is not wrong on their part, we just have a bigger view and a bigger experience often of what is actually happening. (NurU27)

This privilege however resulted in an uncomfortable proximity with the dyad within the home where abusive power was witnessed: "… the at-risk senior is taken advantage of … there's an imbalance of power in those types of relationships with children and their elderly parents" (FGIIU4).

A legal power of attorney [POA] position held an almost ominous power within the home context: "We had to try to get her out of that current situation as soon as possible. Of course, the POA was the person that she was scared of. There is not a lot that I can do…. realistically, he is

the POA" (NurUN8). Some participants described unsuccessful attempts to report such POAs while others attempted to circumvent mistreating caregivers who were blocking access to in-home services.

Unfortunately, truth-finding was challenging. Malintent caregivers offered a façade, hiding the facts:

> He was saying: "Oh mom and dad are so good, I will put whatever care they need into the home", which didn't occur…He was on guard around me… he knew that I was suspecting … on the defense …he didn't want to give me more information than I needed. (SWRUN17)

Following Ontario privacy legislation, practitioners only disclosed patient information when 'significant risk of serious bodily harm occured. Until that time, participants described a burden: "I was privy and I knew that he was leaving them at-risk and there was a risk level. I had a hard time" (SWRUN17). Socialized to protect their patients, they felt helpless holding this secret. Concerns were received from others but sharing could not be reciprocated: "We were getting lots of calls… It would be good to be able to tell the police what is going on. But we really can't say anything" (NurRN15).

Participants treaded carefully as they feared shattering an already precarious situation:

> It's very easy to say intervene but …you rock the boat, and the patient is still in that same situation... So, unless we can totally bubble the whole situation, you have to take caution … to walk gently… we may be putting them in a worse situation than they already were. (NurUN8)

Revealing that one was aware of the mistreatment could trigger more severe mistreatment:

> You are at risk of making a mistake and that could be dangerous… the abuse suddenly going from financial abuse or emotional abuse to physical abuse … it could get worse because someone is stepping in and shinning a light on it. (NurUN22)

Participants therefore maintained their own façade: "I don't really want to say too much because I can get out of there pretty quickly, but I don't want to cause more problems for the patient" (NurRUN4). The most frequent concern described was losing access to the home and therefore the older adult:

> It's a fine line of helping or hindering. So, when you are allowed in, oftentimes you are so thankful just to be in there…you have to be careful because it is really easy for caregivers to say, you are done here. (NurR24)

Domestic Problem within a Societal Context

As outsiders, practitioners did not want to pry into the sanctity of the family: "…he was becoming much more impaired…but … he is happy being at home and OK with paying for the family. We don't feel it's appropriate, but do we have a right to intervene?" (NurRN15). Family boundaries were respected despite beliefs and concerns: "as bad as they are, that might be the only family member they have left" (RtUN23). A participant explained her decision to simply validate her patient's understanding when convinced by her mistreating son that the practitioner was stealing from her: "With dementia… no matter what, he was still her son. It was easier for her to believe that I was the enemy and not her own flesh and blood" (RtUN23).

Out of necessity, as there were no alternatives, family members became 'natural' caregivers, regardless of past family dynamics. Some abused this position: "She was end-stage dementia, non-verbal, was not able to say, and his argument was: If I asked her, she would give it to me no questions asked" (NurUN22). Such attitudes were believed to be socially rooted: "That's how the rest of society sees him… having sacrificed himself for moving into the home, he deserves to get some kind of compensation..." (FGIIRUN1).

The home was described as an uncontrollable context where the mal-intent mistreating caregiver exerted control resulting in unmet care needs: “She had a lot of health issues that were unstable so she was in emerg a lot. We talked about nursing home and he (son) said no, her check is what allows me to live in this house” (NurR10); “He signed the long-term care application at that time…then, (sigh) he refused that bed” (NurUN8).

Risk was greater for rural and northern caregiver/older adult dyads: “…they are more isolated and they don’t have enough services … Things may be going on and there are less people to be aware” (GerR9). Day programs and short-term placement crucial to supporting an older adult with dementia at home, were severely lacking or non-existent: “Nobody here has respite… closest is about 120 km (away)” (NurR10). In addition to the long drive, northern travel was challenging: “a lot of seniors here are homebound all winter long, it’s a hardship” (NurRN14). Longer wait lists for long-term care placement were reported in some rural and northern regions: “…crisis list to long-term care…perhaps hitting his wife because he is so frustrated, I have worked in situations like that… That could be 400 days before she gets in” (RtRUN7).

Rural informal networks could not compensate for formal resource deficits in OAM cases: “What informal service is going to step in? …they are not trained, qualified, or who wants to put themselves in that situation?” (NurRUN4). Although rural neighbours sometimes alerted practitioners in some serious cases, they did not become involved: “A patient came in for a friend of hers; she said nobody is listening to me, but this person is going to die” (NurRN6); “A number of neighbors were quite concerned and kept calling the police” (NurRN15). However, privacy increased the isolation of most rural dyads:

> In a normal situation (no mistreatment), you do see their family or friends, and neighbors help out. But not in a situation when there is neglect or there is abuse. I find the opposite. In a small town, it’s very well hidden. (NurRN6)

Fully understanding what was developing within families was challenging: "everysituation in a home where there's some tension that builds up has its own story" (SWRUN25). This was an uncomfortable place to be with added challenges of truth finding. Privacy of the family unit seemed to reign until the risks became too high.

Interprofessional and Interorganizational Imperative with an Impossible Problem

Practitioners attempted to build a safety net: "…to connect to one another in order to help that person and ensure they are safe" (SWU3). Within this team, there was certainty in maintaining one's traditional role of care practitioner and insecurity in becoming an enforcer: "if we take the heavy hand and be the bad guy, that relationship's compromised and it could have detrimental fallouts if we're not the good guy anymore" (FGIIRUN1). Assumptions were held about the positional power of police and physicians: "If a doctor says she's (older adult with dementia) unable to make these decisions…now the police have something to stand on" (NurUN8).

Ultimately, participants longed for a profession or organization with power to be responsible for OAM cases. However, not yet realizing the futility of this search within the present legal context, and misunderstanding the limitations inherent to their respective roles, they turned on each other. Conflict with police, traditionally perceived as enforcers, was common when this expectation was not met: "They are still not criminally charging anybody… police don't get involved…" (GerRUN5). Not getting involved was perceived as a choice.

Historical conflict lingered with particular organizations, which providing limited intervention, were perceived as not meeting professional obligations: "that's a systemic issue that needs to come from higher up to recognize that at-risk seniors … there needs to be a mechanism for those of us who want to do their jobs" (FGIIU4). Not yet understanding the oppression of the legal context, participants searched in vain to lay blame on each other for the inability to resolve these cases.

When police reached out to practitioners seeking evidence of OAM to warrant entry into a home, practitioners did not disclose information without a patient consent: “they will say we got a call from the neighbor, this is the situation, we want to go in. But we can’t share… (without consent)” (NurRN15). Seeking consent from a mistreating caregiver was especially problematic: “With dementia… you need a family member to consent, but you may or may not have a family member that would allow us to do that” (FGIIU5).

Information was only disclosed in the event of imminent serious danger. To circumvent this restriction, anonymity was attempted. However, police explained they could not enter a home based on anonymous reports: “… the threshold of going in someone's home…If we don't have some other reasonable grounds then...” (FGIIRUN1).

In rural and northern regions, where numerous specialized services were lacking, interprofessional attempts were challenged:

> …our programs are very satellite in nature... The coordinator is here one day a month, maybe two if we’re lucky. We don’t have the consultant that has been hired for the catchment area; it doesn’t include us….so the case management part is really absent in the community…a lot of our other services… all outreach… being a small shop, you don't have anyone that is specialized in anything ... (FGIIR2)

Resignation was apparent when describing the normalcy of rural recruitment and retention challenges. Participants regularly covered vacant caseloads: “…a really long time… Her position will probably still be vacant…we can cross our fingers” (NurR24). Participants expressed understanding why colleagues left: “For years we had a part-time worker whose case load was really crazy and so she was stretched extremely thin. She ended up leaving” (GerR9).

History of Stagnation, Losses, and Systems Failure

Those encountering OAM cases since the 1990s expressed frustration and hopelessness with the stagnation in this field: “Here we are years later, in the same situation we were back

then…and more and more are being faced with the same issues… but nobody feels that there is any use telling anybody because nothing gets done" (FGIIRN3).

During focus groups, participants were unshaken by a case scenario depicting several types of severe mistreatment: "It's unfortunate but we see this more. This case study isn't a shock to anybody around this table" (FGIIRUN1). Although unwilling to abandon this cause, participants did feel defeated by the lack of legislative progress in the province: "So if there's no legislation, that's it. We're still going to be here 25 years later talking about it…" (FGIIU5).

Participants described significant losses including the replacement of police officers, who provided case management and front-line enforcement for OAM cases, by lay persons: "The seniors issues officer was just done away with …That was such a slap in the face for the community, we were devastated" (FGIIR2). Mirror experiences were described in all regions as participants spoke of losing stability, strength and consistency once provided by this senior's issues officer. They also described the progressive erosion of OAM networks once described as "soaring. We got things done" (FGIIRN3). Networks now struggled with less attendance, non-representation of key community partners, inability to case review due to privacy legislation, numerous contextual barriers preventing intervention and sole reliance on the goodwill of members: "it could all easily fall apart" (FGIIR2).

OAM could not be prioritized by participants' organizations. Efforts to combat OAM were therefore self-driven: "That officer who just came out of Police College, very little training. I've been on the job 22 years, getting involved in this (OAM) is self-initiated" (FGIIRUN1). Some participants had received training but it dated back to when OAM was recognized as a provincial priority: "… probably in 2000…17 years ago" (FGIIU5). Participants reported they were working without guiding policies or procedures. One participant highlighted that OAM is presently not anyone's responsibility:

> It's an anomaly this particular field of elder abuse … I don't know that it is on anyone's mandate at this time, clearly identified as being a component of an organizational mandate to address elder abuse. Cases are picked up in fragments. (FGIIR2)

Pressures throughout the health care continuum influenced intervention. Restrictive home care service limits reportedly failed to ensure safety for older adults with dementia: "Our system is broken and cannot meet what these clients actually require … you need to look at the risk levels" (FGIIRN3). When in crisis, caregivers seeking urgent care encountered more pressure:

> By the time they get to hospital, the caregiver cannot possibly take them home... but, it takes longer to get a nursing home bed (from within hospital). So, we work hard to get caregivers to take them home. But they are taking them home in crisis mode ...but that's the way it works. (NurUN12)

When long-term care admission was required, patients with responsive behaviors were often refused. Dismay reigned that institutions had this right: "We encounter that frequently… How or why could they justify refusing an individual because of responsive behaviors when they should be equipped to manage them more than a caregiver?" (FGIIRN3).

Unable to stop the OAM, participants felt that they were failing their patients and part of the systemic problem: "I'm not helping him, I'm just another wall" (SWRN16). Disillusionment with the current socio-legal context was expressed as participants questioned why OAM was not as socially offensive as child abuse:

> A child is locked in a basement, and a senior is locked in a basement, which I experienced…Is it because of the age that it's not looked at? Why? If a child was abused, nobody in society would stand for it! (RtUN19)

Ageism was considered a root cause of the stagnation and losses in this field. This participant explained: "They (older adults) are perceived as a burden… that's why there's a hesitancy to act quickly... seniors are very devalued in our society" (FGIIU4).

Legislative Complexity and Oppression

Participants acquiesced that legal support was nonexistent: "It's not all that much of a legal issue because they don't have laws to protect them" (FGIIRUN1). Difficult past cases revealed historical struggles which created fear:

> My teammate, knew that this woman's niece and nephew were financially abusing her. So, she reported it…but, when they were made aware of it, they reported her to the College of Nurses! She said it was a year of her life that was pure hell …It was horrible what she went through…it really stained her. (NurUN22)

Without specific legislation for OAM, participants shared a complex puzzle of pieces of legislation. The primary piece, the Criminal Code of Canada, was disregarded: "elder abuse is a crime but it's not treated like other crimes… it just seems to be accepted" (GerU28). Participants also described capacity legislation as unsupportive: "The *Health Care Consent Act* came out in '96. We presented to the review board and thought we had tons of information that could support why there was concern. There was no support" (FGIIU5). Next, an understanding of privacy legislation was essential as disclosure without consent violated the law. Uncertainty lingered about interpreting 'significant' risk:

> It's ok if we feel there is significant risk…. we could lose our licenses if we just feel as though there's something happening right? So that's how we break, we don't break the rules because…No it's following the rules right? I probably break the rules. (FGIIRUN1)

Lastly, with cases of OAM complicated by dementia, the only avenue to remove a mistreated older adult from the home for their protection was the *Mental Health Act, 1990*:

> … when it comes to children and youth, we have the authority to apprehend, whereas an adult of course … to take them in custody, to get them help, unless they fall under the Mental Health Act where the legislation kicks in. So there is a lack of authority… (FGIIRUN1)

Despite efforts to understand capacity legislation, training failed them in their complex cases of dementia and OAM: "I've literally attended I would say 20 or more different capacity assessments training. I still have no idea" (FGIIRUN1). Assessing if an older adult with dementia understood and appreciated the consequences of OAM was a struggle: **"**I couldn't really do anything...like nothing. Because she was able to consent to not wanting to move…but, unsure if she understood the ramifications" (RtUN23). Decisions could result in handing decision-making power to a mistreating caregiver: "However, her POA was her son. So, we were shooting ourselves in the foot if we made her incapable" (NurUN8). This action potentially increased the caregiver's power to refuse in-home services and long-term care placement.

Lastly, limited successes with the organizations listed as sources of assistance in OAM guides were shared. Although primarily directed to contact police, the latter clarified specific obstacles:

> There's absolutely no authority for us to be there …That's just the way the law's written ... If that person at the front door says I'm not letting you in my house, unless we can articulate on the threshold of suspicion, it's a lower threshold than reasonable grounds, that we suspect someone inside that house, based on the information we have, is in danger, we have no authority to breach that door. (FGIIRUN1)

Also, most attempts to report a POA not acting in the patient's best interests were unsuccessful:

> It took us a good year to get a new POA, we fought, we reported the POA… I hate to use that term, fighting. I know they want to be of assistance as well. But there are really no guidelines when you are calling and they are very stern on who, what, where, who can access. So, I cannot deem somebody not capable. When we were flagging concerns for them to get involved, it wasn't enough for them…then police didn't get involved. (GerRUN5)

Participants' capacity evaluations were insufficient to justify risk to legal institutions; an assessment from a qualified capacity assessor was required: "If you don't have the capacity assessment, they won't accept it" (NurUN18). The response from these institutions left participants feeling invalidated, frustrated and helpless.

Discussion

This paper shares the analysis of qualitative data generated though a critical research study exploring the experience of professional agency in cases of OAM and dementia within the home with the aim of revealing health care, socio-legal and geographic contextual influences on practitioners' experiences with professional agency. The analysis of contextual influences identified five layered themes, each of which is influenced by those that come after: the privileged burden of seeing behind closed doors; domestic problem within societal context; interprofessional imperative with impossible problem; history of stagnation, losses, and systems failure; and legislative complexity and oppression. The final theme of legislative complexity was found to influence the overall experience and contribute significantly to a lack of practitioners' sense of agency.

Access and Burden

In regard to the home context, participants described a lack of professional agency as they struggled to decipher truths from facades, felt responsible but yet unable to act on the discovered truths, were distressed at witnessing and tolerating abuses of power; and were obliged to maintain the secret of mistreatment until a crisis rendered that disclosure permissible. Although the responsibility of this privilege has been emphasized (Carp, 2000), few have addressed these burdens (Beaulieu & Leclerc, 2006; Bergeron, 1999; Mixson, 1995). Instead, practitioners are sometimes belittled for wanting to protect the older adult and accused of ageism (Harbison, 1999; Phelan 2008; Winterstein, 2012). Participants also described a potentially destructive power they did hold, that of shattering a precarious situation by intervening. Few

studies have previously addressed the fear of increasing risk in OAM cases (Omote et al., 2007; Sandmoe & Kirkevold, 2011). By recognizing the oppressive nature of the hidden domestic context that greatly diminished their professional agency, practitioners became critically aware of their own vulnerability within this context (Sumner, 2010b).

Family and Society

The traditional power of the societal family structure rendered practitioners powerless when crossing this boundary, a notion previously discussed (Phelan, 2008). Nuyen (1994) explains how the historical nature of family caregiving expectations is embedded in ideology and societal structures. Within the current home care system, supportive care is considered a family responsibility versus that of the institution of home care (Statistics Canada, 2012). Participants, having witnessed numerous cases of abuses of power, control, notions of entitlement, and increased risk due to dementia, were powerless against the dominant ideology that family caregiving is best. They also could not change the fact that, within the current dominant social structures of family and home care, mistreating family caregivers, as gatekeepers to the home, have the power to refuse in-home services for the older adult, a reality previously described in other OAM studies (Norrie, Stevens, Martineau, & Manthorpe, 2018; Omote et al., 2007).

This notion of OAM as a family affair was even stronger in rural regions as dyads were increasingly isolated from formal services, a key risk factor for OAM previously identified in rural context studies (MacKay-Barr & Csiernik, 2012; Weeks et al., 2005). This isolation occurred in part due to a lack of day programs and long-term care placement options, essential resources in dementia (Alzheimer Society of Canada, 2010a). These findings highlight a problematic assumption in the literature that rural families, friends, and neighbors can compensate for absences in formal services (Harbison et al., 2005). In this study, the opposite was described. Although some friends and neighbours reported concerns to formal services, they did not become involved in care, considered a private family affair. Isolation of the dyad from

both the formal and informal networks further hid these dyads from the community, a finding echoed by Dimah & Dimah (2003). This notion of possible increased opportunities for mistreatment resulting from the "socio-cultural, and psychological isolation" of rural regions and the assumption that rural communities are hardy, has previously been addressed (Spencer, 2000, p.9).

Collaborative Necessity

Beyond the home and family contexts, the context of health and social services revealed an imperative interprofessional collaboration that was however threatened by lateral conflict. Without critical awareness that their lack of professional agency stemmed from the oppressive contexts within which these cases occurred, lateral conflict, a characteristic of oppression, resulted (Stockwell-Smith, Kellett, & Moyle, 2010). Historical conflict with particular organizations was evidenced, and a gradual erosion of some teams occurred as these players withdrew. As per traditional professional norms and ideologies of power, practitioners held assumptions about each other's roles: nurses, social workers, recreational therapists were carers, while police and physicians held power. Some current OAM Ontario grey literature mistakenly reinforces these traditional ideologies as practitioners are primarily directed to contact police. However, participants refuted this directive due to contextual reasons that are never discussed in these guides, including privacy legislation preventing disclosure of concerns without actual serious imminent danger, the power of the substitute decision maker to withhold consent for care, and thresholds of evidence required for police and legal action. Consequently, when individuals were unable to meet these expectations, they were sometimes perceived as not wanting to intervene. This lateral conflict has not been addressed in the literature. In this study, critical reflection lead to the recognition that the source of their oppression was the ideological discourse dictating that they should be able to intervene, rather than each other. Such subtle oppression must be recognized in order to be overcome (Jacobs, 2014; Sumner, 2010b).

Eventually, participants realized that although all wanted to intervene, all lacked the professional agency to change case outcomes.

In rural and northern communities, the lack of professional resources and normalized recruitment and retention problems challenged services. Consequently, rural practitioners seemed better able to practice "considerateness" for each other, a term Habermas (1976) coined to denote recognition of each other's limits and vulnerabilities when critical awareness is reached. Rural practitioners recognized the necessity to work together because they simply had but each other. These findings have not been addressed in the OAM literature in a rural context.

Historical Losses

As practitioners continued to critically reflect upon the contextual factors impacting their ability to intervene, a collective awareness of larger societal issues emerged. They described historical stagnation and losses in the field of OAM resulting from, they believe, the powerful societal ideology of ageism. Unlike mistreatment of other at-risk populations such as children and domestic abuse victims, OAM within the home has not seen any developments in legislation nor infrastructure in Ontario, but has instead suffered losses. Within societal structures which, historically, have not valued older adults, participants' current oppressive reality consisted of a systemic abandonment of older adults within the health care system, a normalization of risk and valued fiscal constraint in the home care system, the lack of infrastructure assigning responsibility for OAM to any organization, the societal taboo of dementia, and a lack of protective legislation specific to OAM. As health and social services practitioners, some participants had become routinized to such injustice, and resigned to their powerlessness, actions that Sumner (2010b) describes as protective measures when one is oppressed.

Complex and Oppressive Legal Context

The legal context represented the most dominant societal structure impacting OAM. As their complex experience within this legal context cannot be situated within the existing scarce

scientific literature, a summary of the current Ontario context impacting practitioners will be offered. In Ontario, reporting of OAM is only mandatory within long-term care and residential institutions (Hall, 2009). In the home, the *Criminal Code of Canada* (Government of Canada, 2018) is to be used, where crimes "can be reported to the police but a police report is not mandatory" (Advocacy Centre for the Elderly [ACE], 2016, p. 11-12). Therefore, when the OAM occurs within the home, there is no professional or legal obligation to report its occurrence. Participants felt that this absence reveals a disregard for the rights of older adults who are at risk of mistreatment and ultimately, dismisses any one organization or professional from the responsibility to care or intervene.

Conclusions of incapacity were most challenging and this, combined with the identification of risk within the home, created enormous challenges (Mixson, 1995). In Ontario, the different mechanisms exist to determine capacity and in this nuanced context, practitioners experienced powerlessness when their 'capacity evaluations' were not recognized within the powerful legal structures such as the Office of the Public Guardian and Trustee [OPGT]. The provincial grey literature does state that the healthcare practitioner must provide "evidence that the victim is incapable of managing property or personal care" (Wahl, 2013, p. 24). While the latter specifies that evidence "does not need to be a capacity assessment by a capacity assessor" (p. 24), study participants insisted that this indeed occurred in practice. This barrier to intervention by the OPGT has previously been raised as having significant implications (Law Commission of Ontario [LCO], 2015). Furthermore, evaluations of incapacity subsequently lead to the assignment of a substitute decision-maker from an established family hierarchy. This process could then lead to empowering a mistreating caregiver to ultimately control the home, a critique raised elsewhere (LCO, 2015).

Lastly came the potential of violating privacy rights when revealing OAM (ACE, 2016). To disclose without consent, under the *Personal Health Information Protection Act 2004*

(Government of Ontario, 2019b), disclosing personal health information can be done "if the custodian believes on reasonable grounds that the disclosure is necessary for the purpose of eliminating or reducing a significant risk of serious bodily harm to a person (s. 40(1))" (Wahl, 2013, p.28). This powerful discourse, which indicates that the decision must be founded on 'reasonable' grounds versus 'suspicion', an important differentiation of legal threshold between probable cause and possible concern (Skolnik, 2016), severely limited intervention until a crisis happened, at which time, serious harm might have already occurred. Until those conditions were met, the burden of OAM remained on the practitioner.

In Ontario, the predominant narrative surrounding adult protective legislation is one that favours autonomy above all else, with little consideration of risks of dementia and the home context. Attempts to seek changes in legislation have been belittled and references to vulnerability are considered ageist. However, the international literature, especially pertaining to recent progress made in the United Kingdom, and long-standing adult protective legislation in the United States, offer different narratives; one of balance of autonomy and protection and a greater recognition of practitioner knowledge by researchers and policy makers. Key ideological and conceptual differences include the perceived duty to protect adults at risk as they are entitled to the same protection as children (Williams, 2017); the balance to be struck between autonomy and protection (Preston-Shoot and Cornish, 2014); the advantages of making adult protection statutory (Cooper & Bruin, 2017); and the governmental lead in policy developments versus powerful societal institutions (Manthorpe & Stevens, 2015). It is hoped that those changes will incite others to reconsider opposing positions, recognize practitioners as valuable knowledge sources, and stimulate discourse between practitioners, researchers, and policy makers, thereby rectifying the important research-policy-practice gap in Ontario.

Study Limitations

The study was originally designed in phases, with interviews and reflective journals initially planned to be completed before inquiry focus groups began. Themes discovered during data analysis of these first data collection methods could then be shared with the collective. However, due to time and budget restraints, and the aim of face to face data collection, interviews and focus groups were conducted concurrently while in a geographical area. Returning to these regions, some 3.5 hours away on northern roads, would have been inefficient and fiscally irresponsible. However, as the study unfolded, and with the depth and breadth of the data collected from one region to the next, focus groups discussions progressively became richer and the goal of sharing analysis with groups was reached.

Recruitment for focus group participants in some regions was very challenging related to human resource limitations from sick leaves, vacant positions, and reported heavy workloads. Although individuals reported an interest to participate, the size of some focus groups was small. Despite this limitation, the participants present were passionate about OAM and shared valuable contributions.

Lastly, historical interorganizational conflicts in some smaller communities were carried over into focus group discussions. Therefore, some participants were more vocal than others and existing conflicts were rapidly exposed during group sharing. The primary researcher successfully ensured a respectful environment and encouraged participation from all focus group participants.

Conclusion

This study has revealed findings not previously reported in the literature including: the burden of maintaining the OAM secret until disclosure was permitted under legislation, the moral distress of being unable to fulfill their socialized professional role, the incorrect assumption that family, friends and neighbours in rural regions will compensate for formal

service limitations in cases of OAM, as well as the false belief of police and physician power in these cases, the lateral conflict resulting from oppression, the historical stagnation, systemic pressures and losses pertinent to OAM in this province, the challenges with the capacity evaluations/assessments process, and the notions of thresholds of evidence when OAM occurs in the home. These findings warrant future studies.

Using a CST framework, mistreatment of an older adult with dementia, by a family caregiver, and within their home, can be described as the storm where numerous factors combine to create very negative outcomes. This oppressive combination resulted in a lack of professional agency and the lack of advocacy for the mistreated older adult with dementia. As a society, we do not want to believe that older adults with dementia are mistreated by their caregivers in their homes. We also want health care, social services, and law enforcement practitioners to advocate for them and protect them. Yet, the reality is that in Northeastern Ontario, OAM is hidden behind closed doors and practitioners are oppressed within the current dominating societal structures and ideologies which perpetuate this injustice. Only by addressing the pressing need for future research with these practitioners, legislative changes, infrastructure support, and policy guidance crucial to change the current contextual oppression upon practitioners, will we improve the outcomes for mistreated older adults with dementia in Ontario.

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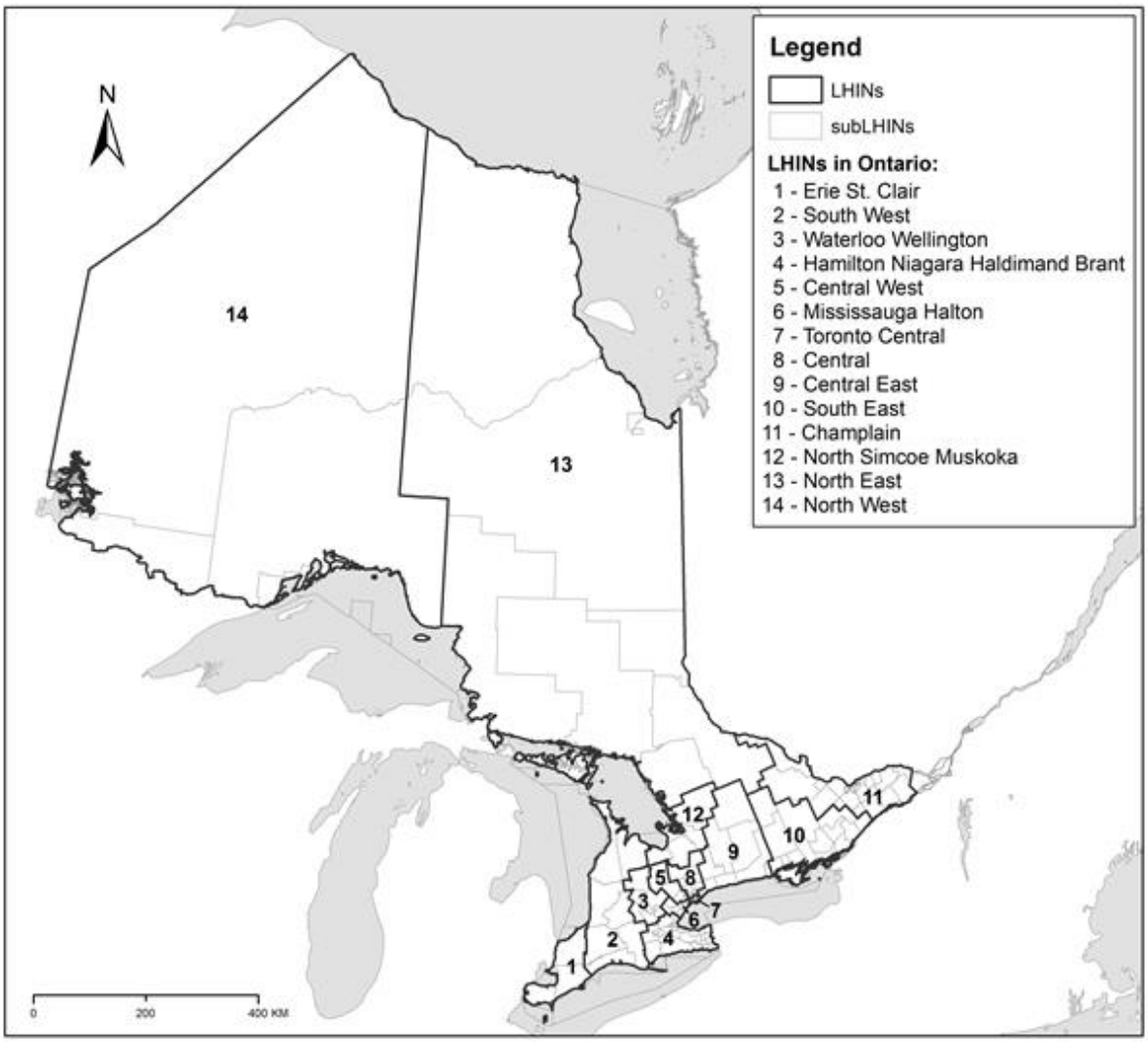
Table 1. Interview participants

Identifier	Rural/Urban/Northern or combination	Discipline
NurU1	Urban	Nursing
NurU2	Urban	Nursing
SWU3	Urban	Social work
NurRUN4	Rural/Urban/Northern	Nursing
GerRUN5	Rural/Urban/Northern	Gerontology
NurRN6	Rural/Northern	Nursing
RtRUN7	Rural/Urban/Northern	Recreational therapy
NurUN8	Urban/Northern	Nursing
GerR9	Rural	Gerontology
NurR10	Rural	Nursing
NurUN11	Urban/Northern	Nursing
NurUN12	Urban/Northern	Nursing
NurRN13	Rural/Northern	Nursing
NurRN14	Rural/Northern	Nursing
NurRN15	Rural/Northern	Nursing
SWRN16	Rural/Northern	Social work
SWRUN17	Rural/Urban/Northern	Social work
NurUN18	Urban/Northern	Nursing
RtUN19	Urban/Northern	Recreational therapy
NurRUN20	Rural/Urban/Northern	Nursing
SWU21	Urban	Psychology
NurUN22	Urban/Northern	Nursing
RtUN23	Urban/Northern	Recreational therapy
NurR24	Rural	Nursing
SWRUN25	Rural/Urban/Northern	Social work
NurU26	Urban	Nursing
NurU27	Urban	Nursing
GerU28	Urban	Gerontology

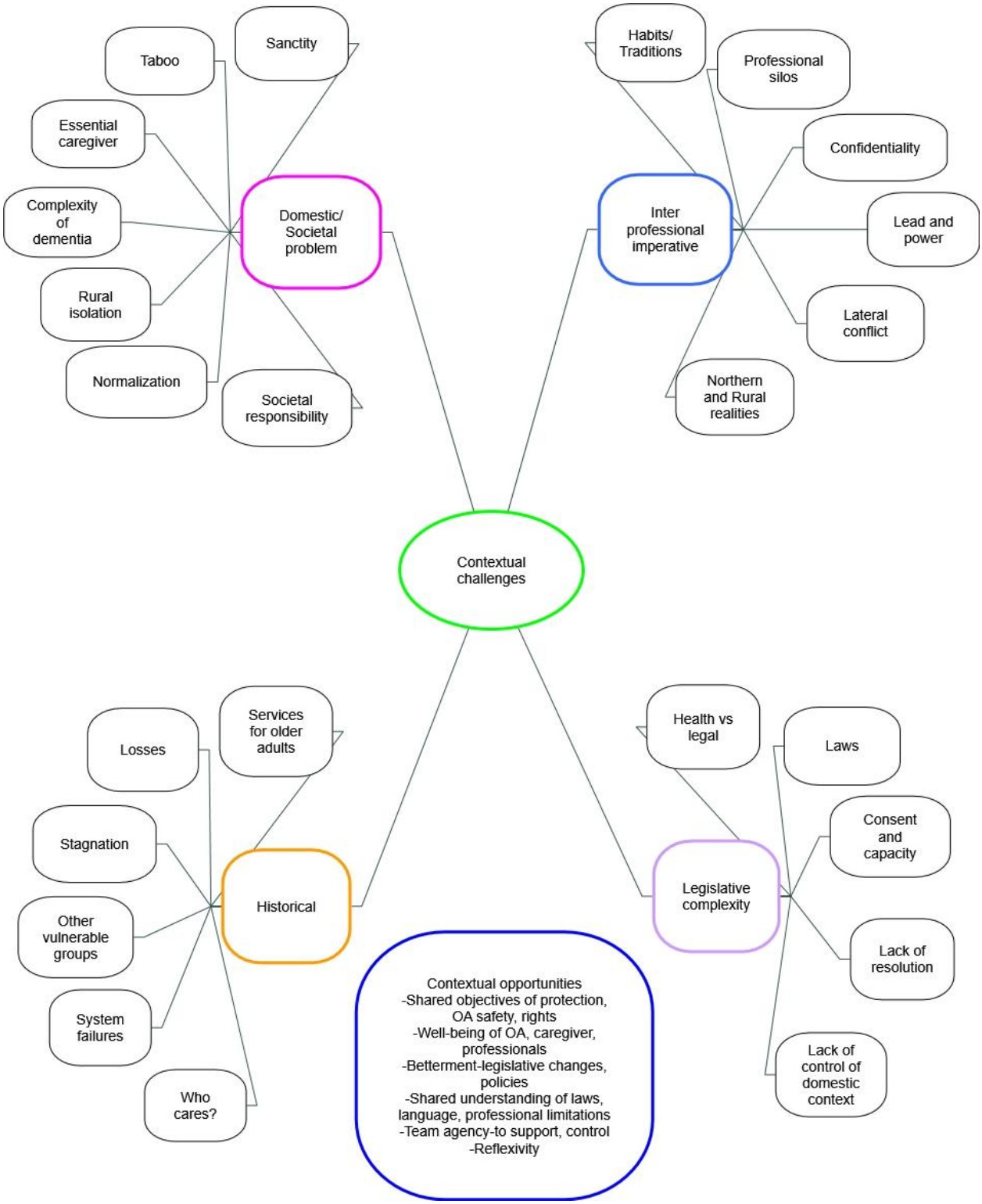
Table 2. Inquiry Focus Groups

Identifier	Rural/Urban/Northern or combination	*n*=29	Years of experience	Disciplines represented
FGIIRUN1	Rural/Urban/Northern	9	6-22	Nursing, Criminology, Psychogeriatric, Domestic abuse, Social work, Gerontology
FGIIR2	Rural	4	10-35	Nursing, Social work, Gerontology, Domestic abuse
FGIIRN3	Rural/Northern	6	5-31	Criminology, Gerontology, Nursing, Business administration
FGIIU4	Urban	3	10-20	Social work, Criminology
FGIIU5	Urban	7	1-42	Social work, Health, Gerontology, Nursing, Corrections

Appendix 1: Map of Northeastern Ontario (Zone 13) Source: Statistics Canada (2015)



Appendix 2: Coding framework: Contextual influences on the experience



Chapter 4: Practitioner empowerment, older adult mistreatment and dementia

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Health care and social services practitioners providing care to older adults who are mistreated in their homes by family caregivers are asked to play a crucial role in ensuring quality care and quality of life for these clients (Anetzberger, 2005; Carp, 2000). A dementia diagnosis further complicates these cases (Alzheimer Society of Canada, 2010a) and may contribute to the hidden nature of this phenomenon (Selwood, Cooper, & Livingston, 2007). Previous research has shown that older adult mistreatment (OAM), without intervention by the practioners who can access the home, can result in a worsening of health if not a hastening of death (Ortmann, Fechner, Bajanowski, & Brinkmann, 2001). However, practitioner's disempowerment in OAM cases has been reported in various socio-legal and political contexts (Beaulieu & Leclerc, 2006; Omote, Saeki, & Sakai, 2007; Wilson, 2002). Further impacting this experience are contextual influences stemming from the health care and social services institutions, the geographical environment and the socio-political contexts which dictate societal and legal expectations with OAM (Bergeron, 1999; Erlingsson, Carlson, & Saveman, 2006; Lithwick, Beaulieu, Gravel & Straka, 1999). Understanding the professional agency of practitioners, their ability to control outcomes and act in a meaningful way (Frie, 2011), and the contextual influences that are required to support them in this work, are essential as both the experience and the contexts ultimately influence case outcomes for mistreated older adults.

To address this issue, the first author undertook a critical inquiry aimed at: learning how health care and social service practitioners experience professional agency when encountering mistreatment of older adults with dementia perpetrated by a family caregiver; discovering how health care, socio-political, and geographical contexts influence the experience; and propelling

practitioners to action thereby improving practice, policy, and outcomes. Findings pertaining to the two first aims, revealing a distressing experience, and within oppressive contexts, are foundational to this paper and have been described in two previous papers (Lindenbach, Larocque, Morgan, & Jacklin, in preparation; Lindenbach, Morgan, Larocque, & Jacklin, in preparation). This paper focuses on the important issue of practitioner empowerment and reports on specific actions that practitioner participants identified to undertake to address their role in OAM management within the care context of dementia cases in Northeastern Ontario. The goals were to infuse provider knowledge and experience into policy.

Background

OAM is defined as "actions and/or behaviours, or lack (thereof), that cause harm or risk of harm within a trusting relationship." (McDonald, 2015, p. 6). This definition mirrors the focus of this study: OAM cases occurring, either in the form of abuse or neglect, between the dyad of family caregiver/older adult with dementia, within the home, where there is a societal expectation of trust, but where this trust sometimes results in abuses of power and control (Choi & Mayer, 2000; Lowenstein, 2010). The negative impacts of OAM can be far reaching, including a downward spiral of isolation, and increased morbidity and mortality (Lachs, Williams, O'Brien, Pillemer, & Charlson, 1998).

The most recent Canadian prevalence study concluded that 8.2% of older adults without cognitive impairment were mistreated whereas international rates varied from 0.8-36.2% (McDonald, 2015). However, in the handful of studies conducted specifically with older adults with dementia, cared for at home by their family caregiver, OAM prevalence rates increase dramatically to 34.9% (Sasaki et al., 2007); 47.3% (Wiglesworth et al., 2010); 52% (Cooney, Howard, & Lawlor, 2006); and 62.3% (Yan & Kwok, 2011). The Alzheimer Society of Canada (2010a) offers a comprehensive review of studies that have assisted in clarifying the risk factors that contribute to this alarming prevalence when dementia and mistreatment coexist.

Furthermore, the projected rise in dementia prevalence in Canada (Alzheimer Society of Canada, 2010b), aging demographics, and the rise of police-reported family violence against older adults between 2009 and 2017 (Statistics Canada, December 2018), demand focused attention on mistreatment of older adults with dementia by their family caregivers.

Knowledge of what occurs behind closed doors can be gained by asking those with access: the health care and social service practitioners who visit the home. This data is limited in the current literature which tends to have focused on prevalence, characteristics of both the mistreated older adult and mistreating caregiver, risk factors and indicators of OAM. Nevertheless, what is recognized is that the experience is complex, that fear and powerlessness may exist, that the burden of responsibility can be overwhelming, and that case outcomes are frequently unfavourable (Beaulieu & Leclerc, 2006; Bergeron, 1999; Omote et al., 2007).

The influences of home health, social services, geography, and socio-legal contexts within which this experience occurs have also received little attention. In Canada, as one in six (17%) older adults receiving home care has dementia with high impairment, experiencing moderate to severe difficulty with basic cognitive and self-care functions (Canadian Institute for Health Information [CIHI], 2010), both the informal care provided by family and the formal care provided by the structures of home health and social services will greatly influence case outcomes. Next, given rural and northern service inequities and challenges (Health Quality Ontario, 2017), it is unknown how rural and northern practitioners experience these cases and what influence geography has on cases.

Finally, in the province of Ontario, Canada, protective legislation currently only exists for victims of intimate partner violence, at-risk adults with developmental disabilities (since birth), older adults in long-term and residential care institutions, and for children (Government of Ontario, 2018a, 2018b, 2018c, 2018d; 2019a). Limiting legislation to these contexts ignores the

fact that many older adults living in their homes are at risk and might need protection from mistreatment.

Methods

This study consisted of two phases: a phase of understanding of the experience and the contextual influences and a phase of empowerment to act upon that understanding. In this paper, data from both phases are combined and presented.

Theoretical underpinnings

Critical Social Theory (CST), (Habermas, 1971), provided the theoretical lens for this study. Based on historical realism, CST proposes that current reality has been shaped by past social, political, cultural, and economic values (Fontana, 2004). It is concerned with issues of power and control, freedom and oppression, as well as dominant ideologies and social structures Harden, 1996). It is precisely in the belief that societal circumstances are historically created and therefore alterable, that lie the goals of CST: to discover this reality, to challenge it, and to move from "what is" to "what could be" (Mohammed, 2006, p. 68).

This theoretical framework was also guided by Habermas' (1984) Theory of Communicative Action. When understanding is reached by meaningful interaction and a coordination of the actions of the agents involved (Hyde et al., 2005), communicative action is reached. All communication should strive towards this critical ideal where emancipation is achieved through collaborative critical reflection and decision-making free from domination (Xiao, Kelton, & Paterson, 2012).

The work of Freire (1972) on critical consciousness and emancipation are both philosophically and methodologically congruent with CST notions of ideology critique and empowerment (Fontana, 2004). Continued critical reflection, dialogue, and action upon the world in order to transform it then leads to emancipation (Fontana, 2004). The latter, defined as understanding who one is and having the collective power to control outcomes, is congruent with

the concept of professional agency (Frie, 2011), discovered to be greatly lacking in the practitioner experience with OAM and dementia (Lindenbach et al., in preparation). Freire (1972) also believed that humans could only actualize themselves collectively. Therefore, the study design facilitated group dialogue and empowerment.

Methodology

The process of critiquing, foundational to this study, consisted of four basic principles: reflection upon one's values, assumptions, and experiences within current contexts; dialectic reasoning which examines social contradictions, and how dominant ideologies and social structures impact one's experiences to make sense between objective and subjective realities; analysis of the constraints upon communication and human action; and dialogue to and empower agents to act (Comstock, 1982; Fontana, 2004; Harden, 1996). The final aim of this study, participant empowerment, was inspired by Fontana's (2004) next 3 principles: democratic knowledge construction; political action to influence change; and with emancipatory intent, where participants were encouraged to question and imagine possibilities. Freire's (1972) writings on education were also respected where participants' sense of social responsibility allowed greater understanding, learning, and fueled a collective commitment to social change.

Ethical approval was obtained from the Laurentian University Research Ethics Board and the ethics committees of all participating organizations. The names of these organizations are not disclosed to protect participant confidentiality as those in small rural regions might be the sole representative of an organization, and to address the concerns of some organizations that policies regarding OAM would be revealed and critiqued.

Sampling

Purposive sampling sought practitioners including health and social care providers, community supports and police officers who had experienced a past case of OAM and dementia within the home by a caregiver. Participants from five Northeastern Ontario geographical regions

were invited. Rurality was defined using the Rural Small-Town definition: "towns or municipalities outside the commuting zone of larger urban centres (with 10,000 or more population)" (du Plessis, Beshiri, Bollman, & Clemenson, 2001). Using data from the 2011 Canadian Census, regions were classified as either rural or urban. Next, although all areas of Northeastern Ontario can be considered "northern" (Health Quality Ontario, 2017), regions were only considered "northern" if winter closures of Trans-Canadian highways prevented access to these communities. Practitioners stressed the importance of this factor in their ability to care for the older adults/caregivers in their care.

Table 1 describes the interview (*n*=28) and journal (*n*=19 of the 28) participants. Then, 29 participants (6 of which had also participated in the interviews) joined inquiry focus groups, described in Table 2. In the Action Phase, 31 participants (who had either participated in the interview or inquiry focus groups, or both) joined action focus groups, as described in Table 3. Various backgrounds are included and participants had worked primarily with older adults between one to 42 years. Overall, 51 practitioners participated and 23 Ontario organizations are included.

Phase I-Understanding

In-depth semi-structured interviews and reflective journals with practitioners who visited mistreated older adults in their homes helped to reveal that practitioners' professional agency was greatly lacking. In its place, practitioners experienced powerlessness to end the OAM in their complex dementia cases (Lindenbach et al., in preparation). Next, inquiry focus groups with practitioners providing supportive community services created opportunities to critique the influences the impact of social, historical, political, and health care contexts on experiences. This sharing revealed contextual oppression from these on practitioners, who, although entrusted to intervene in cases of OAM, reported powerlessness within them (Lindenbach et al., in preparation).

Phase II-Empowerment

Thirty-one of the interview and inquiry focus group participants chose to come together thus combining insights of the experience of OAM within the home, and the contextual influences outside of the home. Four action focus groups were held in urban hubs with rural, northern or remote participants joining either in person or by teleconference. Although a fifth inquiry focus group had been held in Phase I, recruitment attempts could not counter the human resource and workload challenges in one of the five regions. The focus groups began with an education component (Freire, 1972), followed by a political component (Fontana, 2004). A conceptual model, developed by Delp, Brown, & Domenzain (2005) served as a visual tool to demonstrate the relationships between levels of empowerment and community/policy change (Figure 1). All participants, sharing power as agents of change, proposed action projects, discussed rationales, and voted on their preferred action project.

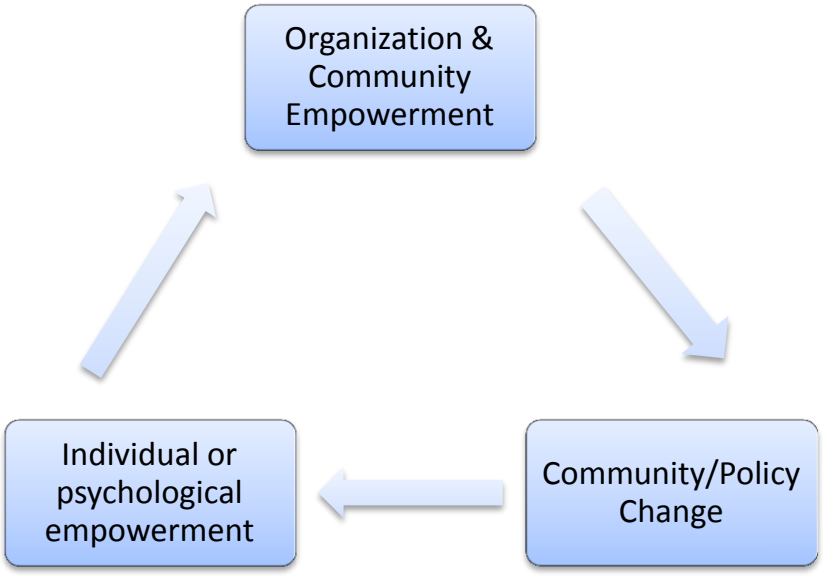

Figure 1: Relationship between Levels of Empowerment and Community/Policy Change (Delp, Brown, & Domenzain, 2005) (Reprinted with permission)

Theoretical Thematic Analysis

The primary researcher (first author) carried out a theoretical thematic analysis on all of the data collected. An iterative process was used throughout data collection to ensure that the

final themes represented collective meanings shared by all participants (Braun & Clarke, 2006). Following data immersion, and guided by the research sub-questions, the theoretical framework, and the researcher's analytic preconceptions, the primary researcher formed initial coding frameworks and began placing data extracts into these coding frameworks using NVivo 11. Revisions of these frameworks continued throughout data analysis of interviews, reflective journals, and inquiry and action focus groups until three final coding frameworks emerged revealing three key themes in the overall study: the experience of professional agency, the contextual influences on this experience, and the need for empowerment. This paper describes the analysis of the third key theme: the need for empowerment (coding framework-Appendix 1). This was followed by an interpretive analysis resulting in the identification of candidate sub-themes which were then repeatedly refined as data extracts were further analyzed resulting in thick and rich themes.

Results

Findings pertaining to this key theme revealed four sub-themes, illustrated as a gradual process of empowerment (Figure 1). Having historically struggled with these cases and contexts, participants began by emphasizing an urgent need for empowerment within the current context. Then, recognizing that participants in other Northeastern Ontario regions shared their experiences, they questioned whether team empowerment would be possible. Next, all regions, unequivocally, were adamant that empowerment could not occur without the support of legislation and infrastructure. Participants ended on a cautious note, relieved to have their voices heard, but careful not to be let down within an oppressive context. Readers may refer to the Tables provided to reference to the participant codes offered following verbatim excerpts.

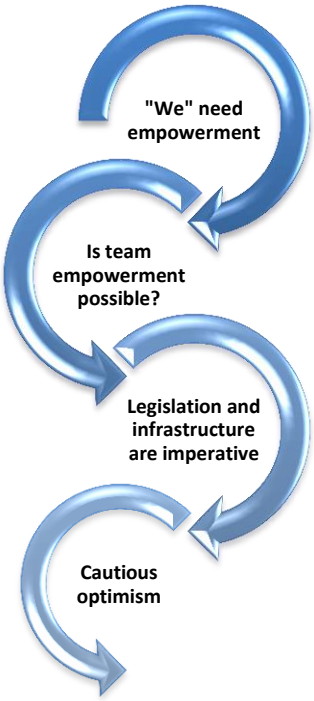

Figure 1: Practitioner empowerment with OAM and dementia

"We" Need Empowerment

Participants described a perpetual cycle of non-resolution, within which they or families unsuccessfully reached out to all available services listed as possible OAM resources: "It discouraged me. You call the elder abuse hot line and they tell you to call the police. And you call the police and they tell you to call the hot line" (SWRN16). Ultimately, case responsibility returned to rest with the individual practitioners or committees. Powerlessness lead to hopelessness: "They would call me and I knew I didn't have an answer" (FGIIIRN2). This admission was reiterated in another region focus group: "Sometimes my blinders go up to be honest because I know that nothing much is going to get done" (FGIIIRUN3). This hopelessness was seen as an erosion resulting from longstanding unsuccessful efforts: "…just being disenfranchised" (FGIIIRN2); "disappointing …people don't find the responses that they feel are appropriate for what they're seeing" (FGIIIUN4).

As participants from different backgrounds shared their obstacles, previously held assumptions of positional power were replaced with a new understanding that all were powerless within the existing contexts: “She (police officer) had huge concerns but they said there wasn’t much they could do. Because she (older adult with dementia) was agreeable for them (mistreating sons) to be there” (NurRN15). Participants who had maintained hope for provincial legislation permitting them to resolve cases described the public’s expectations of protection:

> … we are a fluff...(the expectation is) that we're going to come in as a group and go walk into that and take care of it?
>
> (other) A lot of people think that too when they call.
>
> (other) That's what we were hoping to accomplish.
>
> (other) … 25 years later, there's nothing in place. (FGIIIRN2)

Participants were adamant that provincial efforts needed to change from their current focus on education to one of intervention:

> I'm sick of being told… I can tell you verbatim everything about abuse. I could tell you the sexual abuse, emotional, all that, but ask me what to do about it and I go blank. I don't know what the hell you do about it, I just know it exists. (FGIIIU1)

This was especially true in cases of dementia where the lack of provincial supportive legislation failed to address the complexity of their cases: “This is what we always say, it’s great that it’s on everybody’s radar. But when your hands are tied, there is not a whole lot you can do about it… with people with dementia, (its) not so easy” (FGIIIUN4).

Some participants had recently attended a provincial program, again focused on education about OAM. Given their vast knowledge and experiences with challenging OAM cases, many were angered and saddened by this focus which they viewed as repetitive and stagnant:

> Did we not feel that when we were at that? (title of provincial training) It just hit us like a ton of bricks that we've gotten nowhere and we're still nowhere… (agreements from group) …Sad eh? That was awful. I walked away from that going this was the worst experience I've had. (FGIIIRN2)

Not only did practitioners want to be empowered, but they also advocated for caregiver empowerment when lack of respite contributed to OAM: "The caregiver becomes at-risk and at risk of potentially harming… we try to avoid hospital admissions but sometimes, the risk is too high because of the limitations of (in-home) services" (FGIIIU1). Again, participants witnessed the impending crisis: "I had one son say to me: I'm on the brink of… I'm going to, something bad is going to happen" (NurRUN20). Participants felt that important research and policy documents promising increased caregiver support, which should inform home care decisions, seemed to be ignored: "It's almost like there's a sense of apathy in spite of all the reports like the *Rising Tide Report*. We know that tsunami's already here, it's not coming, it's here. The system just doesn't recognize it" (FGIIIUN4).

This participant explains the precarious situation created for caregivers coming to her support group due to insufficient in-home respite:

> When people come to our group, do you know the stress that they go through? checking their watch, they're checking the clock. A lady, when she got back home to her husband, the worker had left, … she was 10 minutes late. He had diarrhea all over … so, is she excited about coming next week without worrying about him? (SWRN16)

Participants pressed for the system to recognize caregiver needs: "We're saying to 84-year-old mom … that's your husband with Alzheimer's, good luck, we'll see you to bathe him twice a week for half an hour! Really, they need more support!" (FGIIIRN2).

Is Team Empowerment Possible?

Participants began understanding the obstacles encountered by their colleagues. A police participant explained others perceptions of his lack of action:

> If we couldn't get in the house to verify, it's sometimes interpreted as if the police didn't do anything… that's not the case; there's very limited legislation when it comes to trespassing into someone's home without prior judicial authorization, without warrant or otherwise. (FGIIRUN1)

This obstacle was also evidenced after a case study was presented to the focus group. In it, a neighbor had called police after hearing screaming from the home: "Police action is very evidence-based so the neighbor hearing a scream the night before, it's not evidence to allow us to take further action" (FGIIIRUN3). Different understandings of the concept of evidence highlighted the complexity of working in interprofessional teams where practitioners are socialized in their own language.

Participants discussed a second obstacle to teamwork, the belief that specific organizations could but would not increase services. However, new understandings emerged as all shared disapproval and the inability to change their own restrictive guidelines. One participant described recognizing a colleague's fear:

> She said, well I thought there may be (OAM) but I wasn't sure … I think she was afraid of what might potentially come of it all, and didn't have the comfort level to deal with it. So, when I stepped in, she was relieved. (SWRUN17)

Despite this recognition, factors such as workload impeded teamwork: "I feel bad saying that but, especially up here, in this area, the caseloads, the work that we have, I don't find it's practical…" (FGIIIRUN3). The lack of tangible outcomes was also a barrier: **"**It's discouraging for us, as a group to sit at round tables, always come up with the same issues and never a resolution" (FGIIIU1). Again, the notion that practitioners were powerless to effectuate change

until a crisis occurred surfaced: “You can guarantee that everyone here …We tried this, we did this, now what? And then we wait (for the crisis)” (FGIIIRUN3).

The success of teamwork sometimes entailed breaking/bending the rules: “People can be very creative… in terms of how to get people services that they don't really qualify for. There are people willing to go above and beyond that rhetoric” (FGIIIU1). However, bending the rules was risky: “I thought, I will likely get called on that but this is patient focused and is going to work…and it did” (NurU27). Although participants were uncomfortable with rule bending/breaking, it was justified “when you're worried that somebody's safety is at risk” (FGIIIU1); it’s “being there for that senior” (FGIIIU1).

Next, participants wanted to abide by privacy legislation when working together, a root cause of past failed attempts to teamwork: “We did have a case review team, but we were breaking rules…everybody knew who you were talking about” (FGIIIRUN3). Unable to disclose information with those outside the health and social services team, practitioners wanted to be able to share concerns legally: “…significant weight loss, bruising, multiple falls…you start questioning, like with children, constant emerg visits… Why are they always in a delirium? What's going on? An officer's not going to be able to identify that” (FGIIIUN4).

> Some suggested that a non-specific disclosure to police but others expressed caution:
>
> I may not be able to say to him (police), it showed on Meditech that this person has broken their arm x times …I could say, ok there's really something going on, I can't specify, but …
>
> Other: You'd have to be very careful. (FGIIIRUN3)

Interestingly, participants in northern urban hubs, that also serviced the smaller surrounding rural communities, described advantages to teamwork not shared by those strictly rural or urban participants in the study. They described a tight network where collegial relationships prevailed: “Knowing who to contact and already having that relationship built with

the service providers. I was able to call in key people that I knew could help me intervene…and they knew to call me" (GerRUN5). The ability to trust other members of the team was key: "There is also the element of trust …you know that they are good. So, you trust their judgement …that what they are doing is in the best interests" (SWRUN17). This positive team environment contributed to a safety net:

> In Northern Ontario, I find that people, once they are in the system, there is less chance they will fall through the cracks… we kind of catch them to do a follow up or make sure someone else is doing a follow up. I think it's because there is just more relationship between services and fewer people working for services. (RtRUN7)

Legislation and Infrastructure are Imperative

Despite attempts and goodwill to work together, the lack of specific OAM legislation was an overwhelming obstacle to entering a home and intervention. Comparisons were made with legislation for the protection of children as participants reiterated that mistreatment was unacceptable, regardless of age: "A parent can't abuse their child, a child should not be able to abuse their parents. I don't think it's that complicated" (FGIIU5). This police participant explained how specific legislation for children supports interprofessional practice and entry into the home:

> With CAS (Children's Aid Society), there's a legislative authority, that's the difference…we rely on their (CAS social workers) information to establish our grounds to believe there's a child in need of protection …that authority kicks in under the Child Family Services Act. (FGIIRUN1)

Overwhelmingly, participants felt that they, like CAS workers, should also be "relied upon". Discussion continued regarding suspicion versus evidence: "Unlike children, where suspicion is sufficient to warrant police investigation, here, we need proof that that fracture is due to OAM before involving police" (FGIIIRUN3). Participants longed for similar supportive

infrastructure: “They have legal counsel, they are guided, they have supervisors, they have guidelines, we have none of that…this system isn't built that way. In fact, it's not built at all” (FGIIRUN1).

Ultimately, participants wanted the ability to protect mistreated older adults. Aware that this entailed a possible connotation of ageism, caution prevailed:

> We need to systemically move a little bit more to that end where, if in my professional opinion, this person has cognitive impairment and is not able to make informed decisions… I will ethically do my due diligence to protect this person. (FGIIU4)

Borrowing legislation from other at-risk groups was a strategy used when applicable. This police officer describes applying domestic violence legislation with mistreated older women, where an intimate partner relationship existed:

> If that person's partner or intimate partner for example is the culprit, we can pursue that person because it falls under the domestic violence say criteria. (But) if that person's son, daughter or caregiver (is the perpetrator), where there's no intimate relationship or never has been, then the domestic violence process does not apply. (FGIIRUN1)

When domestic legislation was not applicable, and the *Criminal Code of Canada* was the only legislation supporting legal intervention, evidence of crime and capacity had to be considered: “Information from the victim…it all boils down to that…disclosing what happened and to report it for criminal investigation… if the victim, being of sound mind, does not want it pursued, ultimately our hands are tied yet again” (FGIIU4).

Nevertheless, borrowing interventions from domestic abuse was problematic. For example, placing someone with dementia in a women’s shelter, a frequently cited intervention in provincial handouts, was deemed inappropriate: “We cannot force her to come to the shelter…and when you take somebody with dementia out of their routine and area … there's so many risks” (FGIIIRUN3). These shelters would fail to meet the needs of these older adults: “I

am not going to put a dementia patient in the shelter. (They need) people who are trained in dementia care, twenty-four-hour care" (GerRUN5).

Participants could not understand why older adults could not be addressed in their own legislation when dementia created risk: "There is no adult protective services act, unless it's for the developmentally handicapped. It's just a sort of a sense of well, why isn't there?" (FGIIU4). Overwhelmingly, it was felt that this province failed mistreated older adults with dementia. Some spoke of the resistance to recognize dementia as a risk:

> They changed the laws around domestic abuse so that you no longer had to have the consent of the victim to press charges …You don't ask for consent in a child abuse situation. But sometimes, we almost have to treat adults as if they are eight years old, because we have to be where that person is (in their dementia). (FGIIIUN4)

Participants were cautious in this discussion, verbalizing that rights to autonomy for capable older adults had to be maintained. Others verbalized frustration with a system that frowned upon the protection of the older adult at-risk but where outcomes were unfavorable. They believed the current context failed to ensure their right to protection:

> It is a tough balancing act but our laws currently sway in the wrong direction. We need to strive towards a society where we recognize (that) people with dementia, that have limited or no capacity, have the right to protective services. (FGIIIU1)

Although initially cautious with such statements, they eventually expressed this with conviction: "We're told: my dad has rights! But he has a right to be protected, he doesn't have a right to be abused" (FGIIIRN2).

Participants clearly perceived a responsibility to protect those at risk: "Once I know, I have to act, I feel it's our duty to each other and (our) human responsibility to not turn away" (FGIIIRN2). However, they did not believe that society acknowledged this responsibility:

> We're a backwards society, let's face it. You could abuse your kids but you couldn't abuse your dog before. There were laws created to protect animals before children. That legislation existed in the late 1800's however the Child Protection Act didn't come to be until the 1980s. (FGIIU4)

Legislation and infrastructure were believed to be essential to unequivocally recognize the protection of older adults at-risk as someone's responsibility. Until OAM had its own specific legislation and infrastructure, it would remain unrecognized by society and unaddressed by government: "It's (management of OAM cases) not directly part of our mandate, so it's being picked up in fragments but there's no way to say to the government, this is costing your society this much money. There's no data" (FGIIIUN4).

Cautious Optimism

Discussing findings provided in the Interim report helped participants realize that they were not alone: "I thought, all these people are saying what I've been through…all these years…it's never really been down on paper in such a reality… all these things that you've already been through and felt helpless" (FGIIIRN2). While this shared experience was reassuring, some worried: "There's nothing we can do, we might as well… just what are we going to do? Just turn our eyes away? it was awful. I felt that way, reading everybody's scenarios" (FGIIIRN2). However, this commonality served to propel the focus groups to action as they shared "the same vision", and were "not alone" (FGIIIUN4).

Action projects. Participants chose to act upon five regional projects on policy, community action, practice, and caregiver/older adult outcomes.

1. Policy brief for adult protective legislation and infrastructure. The need for OAM protective legislation was the strongest conviction linking not only participants from one

individual region, but all regions combined. They shared their frustrations freely, although difficult to hear:

> If we were kicking a dog or a child, (moans from group), exactly, it's prescribed. But you kick an elderly person, and she says, no I'm okay with being kicked, nothing … It's just so frustrating to work in this field! (FGIIU5)

Legislation was deemed essential for OAM societal recognition: "We do have a youth bureau which are dedicated officers servicing youth situations but we don't have the same for elderly people" (FGIIIRUN3). Infrastructure was needed: "It's about protecting the well-being with the purpose of educating, providing resources and repatriating families … like CAS, they're in the home, you can't say no, they're authorized to go in under the law" (FGIIIUN4).

2. Sensitize community leaders to dementia as risk factor for OAM. Policy change was required at a community level where political leaders failed to recognize dementia:

> There was nothing with regards to dementia … this plan passed by council…Age Friendly Communities, what a waste of money…I was just appalled. I really think that's where it has to start…if you haven't got your community leaders actually invested in knowing who lives in our community and what those people need, then we're floundering…we're still going to be sitting at committees ten years from now having the same conversation. (FGIIIUN4)

3. Talking-the-talk. The next action pertained to a shared interprofessional language with OAM, dementia, capacity, and risk: "We are credible but yet…. in health care, we need to be comfortable with what terms they (police, lawyers) use…that gives us credibility" (FGIIIU1); "Knowing the legal jargon…so I'm not completely overwhelmed and fearful...What do I need to empower myself?" (FGIIIUN4). The adoption of shared evidence-based tools within the interprofessional team could then provide assessment reliability: "Tools…multiple providers, we

come together, compare answers and talk (it) through… comparing notes so it's not just my call, but it's a team" (FGIIIUN4).

4. Creation of a situation table. The next proposed project was the creation of a situation table. Although some OAM networks existed, most had abandoned case reviews with the only remaining one in Northeastern Ontario described as: "pretty weak right now … hasn't been very active" (FGIIIRUN3). The engagement of key powerful legal players in OAM and an approach to respect privacy legislation were essential challenges to this project.

5. Project to support caregivers. The final action project aimed to recognize caregiver respite as a means of preventing OAM: "I have seen some of the best-grounded moral people fall to this risk factor" (FGIIIRN2). Participants stressed the need to rethink current home care service: "They (caregivers) should really be recognized … in the present system they're not" (FGIIIRN2). Although the current system provides some support and education programs, in-home respite hours and day programs were insufficient; caregivers needed "so much more than what we can provide" (FGIIIUN4).

Persistence and hope. At the conclusion of the study, participants remained cautiously hopeful:

> It was cathartic to speak with you and I felt that maybe we are seeing some progress. We all have very innovative ideas but it seems that no one is in a position to implement them. As I am putting these feelings on paper, I know that someone out there is being neglected and abused and we are not doing enough to help them. (FGIIIRN2)

Despite the long-standing challenges in this field, participants remained committed: "I've been in this position for 31 years, and I've seen people come and go … all have that sense of commitment and investment … never throwing up our hands" (FGIIIRUN3).

The shared experiences they had within their communities, and within the five regions of the study, inspired a collective strength: “We can't stop, even though we feel that our hands are tied in several cases, we can't stop” (FGIIIUN4). Participants ended the study being hopeful “to obtain a voice in affecting change to improve quality of life for persons identified in this study” (FGIIIUN4). A collective, although tempered, hope remained for the safety and protection of older adults with dementia mistreated within their homes in this province.

Discussion

This study aimed to firstly understand the professional experience of agency by practitioners encountering mistreatment of older adults with dementia by their family caregivers and the health care, socio-political and geographical context influences of rural and urban Northeast Ontario, and secondly to empower practitioners to act upon changes in the socio-legal health care context to increase professional agency. Participants described their need for empowerment, the necessity to collaborate with other practitioners, and the requirement of legislation and infrastructure. Lastly, they chose to undertake action projects to empower themselves, change their communities, and influence policy change within this province.

Powerlessness

The first theme, practitioners needing empowerment, reveals a societal contradiction: the assumption that practitioners have the power to resolve cases of OAM as opposed to the inability participants described in protecting mistreated older adults with dementia in their care within a perpetual cycle that they were powerless to break. Although guidelines are offered in provincial handouts, it is in their application that flagrant flaws were revealed by participants. One commonly recommended intervention in the grey literature was reporting concerns to police, some even adding that an anonymous report was acceptable (Community Legal Education Ontario, 2018; Ministry for Seniors and Accessibility, 2016). However, this strategy would not be helpful in the home context due to the required threshold of reasonable grounds to warrant

access (Skolnik, 2016). Furthermore, as the only means of laying charges was the *Criminal Code of Canada* (Government of Canada, 2018), evidence that a crime was committed was required. Beaulieu, Côté, and Diaz (2017), in an action research project with police in Montreal, Quebec, a legal context also without adult protective legislation, described the scarcity of research on police roles, needs and contributions to interprofessional OAM efforts. Without this recognition, there is no understanding of their practice challenges. A second recommended source of assistance, contacting the provincial Seniors Safety line, frequently lead to a problematic provincial cycle of perpetual ineffective referrals as no one entity had the power to stop the OAM. Participants in this study were therefore limited to interventions to mitigate risk, a finding previously reported by Lithwick and colleagues (1999) with their practitioners in a similar socio-legal context in the province of Quebec, Canada.

Since 2002, the provincial system's patterned response has been to repeatedly provide education on what OAM is, its forms, indicators, and risk factors. This drive surely stems from research conclusions that practitioners require more knowledge on OAM and education to shift their attitudes (Harbison, 1999; Payne, 2008; Podnieks & Baillie, 1995; Stones & Bédard, 2002; Vandsburger, Curtis, & Imbody, 2012). However, in an American study looking at variables predictive of appropriate clinical decision-making, years of experience and applied knowledge, not education, significantly influenced OAM recognition and intervention (Meeks-Sjostrom, 2013). When considering the high level of knowledge held by these study participants, the assumption of lack of knowledge is misguided and has the effect of devaluing their struggles with these cases. Nonetheless, those without power to change the legislation and create the corresponding infrastructure cannot be faulted for repeatedly delivering this education. The public certainly requires education about OAM and new practitioners require this sensitization as it is seldom addressed in post-secondary education. However, participants in this study, fully invested in OAM efforts, pleaded for the province of Ontario to finally push beyond the envelope

of education towards that of intervention, legislation, and infrastructure. As per the broad social view of CST, it is the context where the phenomenon is occurring that must be changed, for without that change, the phenomena will persist (Fontana, 2004).

Team Challenges

Although individual professional agency was not achievable in OAM cases where practitioners could not control outcomes, they knew that collective action was required for empowerment. CST led to a critical understanding that the contextual oppression they worked within, rather than each other, was the source of lateral conflicts (Freire, 1972). The road to this understanding was not easy as interpersonal and interorganizational conflicts were openly shared. Literature on conflicts between practitioners in OAM cases could not be located.

By discussing challenges to teamwork, participants shared how bending/breaking the rules regarding service limits, eligibility criteria and confidentiality occurred. Not previously addressed in the OAM literature, such rule bending has been described with other health-care practitioners as a coping mechanism when experiencing moral distress in a situation they cannot control (Corley, 2002; Kontos, Miller, Mitchell, & Cott, 2010). Although possibly bringing about positive outcomes in an OAM case, the professional risks that some practitioners were willing to take to protect the mistreated older adult also resulted in corroding future collaboration when rule bending/breaking was expected but ceased to occur.

Even though practitioners believed in an interprofessional, interorganizational approach to OAM, some challenges seemed impossible to overcome. Involvement in OAM efforts, not included in any organizational mandate, was self-driven, based on personal beliefs and values of dignity and protection. This represented Habermas' (1976) concept of moral consciousness as they questioned policies, and advocated for older adults (Sumner, 2010). The lack of organizational 'ownership of OAM case responsibility' in Ontario and resulting self-driven efforts by practitioners, have not been previously addressed in the literature.

Despite this, a contributor to successful collaboration was discovered with those practitioners and teams that were a combination of rural, urban and northern who described tighter knit teams, where practitioners spoke of trust, a necessity to rely on each other due to scarce resources, knowing who they could call upon for assistance, as well as serving as a safety net to catch older adults when OAM reached its inevitable crisis. These findings echo those of others who have described positive working relationships in Northern Ontario as a "northern advantage" (Health Quality Ontario, 2017). However, in strictly rural regions, resources were insufficient to create this local team and practitioners struggled with this sole burden.

Need for Legislative Supports

Next, as OAM does not rest on its own legislation and infrastructure in this province, practitioners are expected to have, and be correct in the application of, knowledge of numerous pieces of applicable legislation, complex legal knowledge that falls outside their scope of practice. These demands have not been addressed in the literature. Furthermore, privacy legislation, although facilitating the sharing of information in cases of imminent and serious harm (Solomon, 2009; Wahl, 2013), was an impediment to addressing cases before they reached that severity. Although Ontario practitioners have been reproached for not understanding privacy legislation thus legitimizing inaction (Wahl, 2013), information disclosure and confidentiality have been reported as critical limitations by practitioners in similar legal contexts (Beaulieu et al., 2017). The ethical implications of being prevented to disclose concerns of mistreatment, prior to a crisis, demand to be addressed.

Participants pressed for protective legislation for older adults rendered at-risk by dementia living within their homes, as it currently exists for older adults in Ontario long-term care and residential care (Government of Ontario, 2018b, 2018c; Hall, 2009). Participants argued, as have others, that providing intervention in cases of OAM is justified just as are domestic violence and child protection legislation (Bergeron, 1999).

Older adults' right to safety was viewed as a basic human right currently not being ensured for at-risk older adults remaining in their home. This is keeping with the position of the Ontario Human Rights Commission (2001) with the Canadian Association for the Fifty-Plus and that "elder abuse and neglect should be identified as abuses of human rights" (p. 67) and recommendation that "mechanisms currently in place to address other forms of familial abuse should be extended to apply to elder abuse" (p. 72). However, in some Canadian grey and scientific literature, those advocating for older adult protective legislation have historically been accused of ageism (Harbison, 1999). For example, Advocacy Centre for the Elderly [ACE], (2008) stated:

> …due to their (health practitioners, social service agencies and policymakers) misconceptions, they often purport to act in the best interests of a at-risk adult, but…instead of working with the senior who may be "at-risk"…they may breach privacy, take action with which the senior does not agree. (p. 9)

We need to address the experience that the dominant ageism rhetoric subtly oppresses practitioners who dare to advocate for protection. It stifles their efforts and makes them feel that they are unfairly judged or criticized for suggesting the need for older adult protection. On the contrary, participants stressed how interventions to protect a mistreated older adult with dementia were those of an ethical and good professional, not of an ageist one. In fact, the lack of protection offered to older adults compared to that offered to other groups was perceived as systemic ageism as it perpetuated a lack of societal value for older adults. This province's socio-legal context oppression on practitioners has not been considered in the literature.

In provincial guidelines, an ethical delineation must be drawn between principles of care for two starkly different populations that are seldom considered apart: upholding the autonomy of those older adults who are capable of choosing to remain in a situation of mistreatment, and providing protection for older adults with cognitive impairment who cannot choose to accept the

mistreatment. Anetzberger (2000) explains that although an empowerment approach is appropriate with independent victims of OAM, a protective approach is needed when cognitive capacity is challenged. Similarly, Hall (2009) warns that: "Refusing to recognise and provide for this real difference, pretending that older adults are 'just like' younger ones and therefore just as 'good', is itself a form of discrimination" (p. 40). Others have also begun to question if the predominant victim empowerment model in many Canadian provinces is missing those older adults that are most at-risk of OAM (MacKay-Barr & Csiernik, 2012). Two aspects were especially problematic for practitioners in these cases: having their concerns about vulnerability, impaired capacity, and risk validated within a context where they were powerless; and being unable to stop the mistreatment until cases reached a crisis (Lindenbach et al., in preparation).

Acceptance of the need for legislation in this province must begin with changing the accusatory narrative whereby the dominant ideology of ageism infects all attempts to implement adult protective legislation. The legal reform occurring in the United Kingdom, where duty to address OAM is "owed" to older adults (Spencer-Lane, 2010, p. 45), placing it "on par with child protection" (Williams, 2017), could lead the way to a system of adult safeguarding that provides "equal access to justice and protection systems while fostering their safety, autonomy and confidence" (p. 156). Cooper & Bruin (2017) cite that placing adult safeguarding on a statutory footing not only ensures the protection of adults' rights to live free from mistreatment, but it has resulted in the doubling of referrals to 100,000 in the first six months following the enactment of their legislation. Specific components of the UK legal reform, which vary slightly in the different UK nations (Scotland, England, Whales have legislation, while Northern Ireland has a policy framework), but could be used for Ontario legal reform are: the statutory assignment of a lead role to an organization who is responsible to ensure investigations are carried out (Spencer-Lane, 2010; Williams, 2017); the designation of OAM as a specialty, versus a generic expectation of all practitioners (Stevens et al., 2017); legislative duties such reporting and investigating, powers

of inquiry, of entry in the face of hindrance, protection orders (Mackay & Notman, 2017; Stevens, Martineau, Manthorpe, & Norrie, 2017; Williams, 2017); and the implementation of safeguarding adult boards reviewing circumstance and statutory parners' actions in mistreatment cases resulting in harm or death (Cooper & Bruin, 2017). It is hoped that the province of Ontario can recognize the need to introduce adult protective legislation including similar infrastructure to support practitioners in their efforts.

Hope and Action

The final theme was one of cautious optimism. Ruangjiratain & Kendall (1998) explain that critical research is inadequate without some engagement in social or political action. This two-phase study concluded with five projects chosen by practitioners to improve outcomes for older adults with dementia who are mistreated within their homes. Although unable to complete the projects within the time constraints of this study, the first author has committed to continue to work with the groups on their projects.

Firstly, all participants, regardless of geographical region, overwhelmingly chose to collaborate on a policy brief to be forwarded to federal and provincial politicians and influential professional bodies. This brief will therefore represent the Northeastern practitioner voice identifying the challenges of lack of infrastructure and legislation specific to OAM in this province. A second group envisioned a grass-roots project to sensitize their community leaders to OAM and dementia. Crucial in their region where leaders did not seem to recognize the need for dementia-friendly communities, this aimed the creation of a strong united practitioner voice to town council. Thirdly, a group chose to address the need for a shared professional language and the use of evidence-based screening tools. It was felt that shared linguistic conventions by all practitioners, police enforcement and legal representatives, would lead to desirable outcomes of credibility, lateral conflict resolution, reliability of assessment, shared understanding and collaboration. The fourth action was the development of a situation table, where OAM cases

could be presented to strengthen networks by equalizing all members in terms of contributions, input, discussion, strategies and planning. It was hoped that the adoption of a four-filter approach (Government of Ontario, 2018e), married with the level of risk, would result in the ability to discuss cases while still respecting privacy legislation. The final action is aimed toward the development of an innovative caregiver support project to address current insufficiencies in the home care system to address caregiver stress with dementia. Practitioners wanted to be able to offer sufficient respite to caregivers, reaching those who were isolated, before a crisis of OAM was reached.

At the conclusion of the study, participants were encouraged to act on their projects as they felt empowered. According to Lincoln, Lynham, & Guba (2011), therein lies evidence of validity of CST research. They saw possibilities beyond their limited situation. However, they remained doubtful, having been devalued in the past within an oppressive context where their efforts could not protect the at-risk mistreated older adults they cared for in their homes. This study provided some hope that "someone was listening". These notions have not been addressed in the literature.

Limitations and Conclusion

Some study findings have not been previously discussed in the literature. These include: a perpetual cycle of non resolution and self-driven efforts related to the lack of ownership of OAM occurring in the home in this province, the problematic assumption of practitioner lack of knowledge, the bending/breaking of rules occurring when unable to resolve the OAM, the unrealistic knowledge demands on practitioners to be competent with numerous pieces of legislation, practitioners' perception of lack of adult protective legislation as a form of systemic ageism, and the importance of validating practitioners' experiences. These findings merit further investigation.

This two-phase study was fruitful due to the time shared with participants in face-to-face interviews, inquiry focus groups and action focus groups and repeated travel throughout Northeastern Ontario. However, this extensive travel and data collection within the one-year window of this funded design resulted in insufficient time to accompany groups with their action projects. As per Choudhry and colleagues (2002), in addressing empowerment, ongoing support and energy are required to ensure and sustain action for change. The primary researcher will therefore continue to assist with the action projects outside of this study.

Attempts were made to have participation from all geographical areas in the target Northeastern regions and all pertinent home care, social services and police enforcement. However, recruitment was challenging, especially in some rural and northern communities with limited human resources and due to workload challenges in all communities. Despite this limitation, this is the first Ontario study to ask front-line practitioners about their experience with OAM and dementia.

A third limitation was creating what Bevan (2013) names communicative spaces in critical research guided by Habermas' CST. Within such spaces, a collaborative reinterpretation of each other's experiences can occur through dialogue, leading to greater richness and depth of understanding. Although focus groups were designed with this goal in mind, some obstacles served as deterrents: workload obligations which resulted in last-minute cancellations and smaller size focus groups; urgent caseload issues which interrupted some participants during the focus group time; and long-standing lateral conflict with some organizations resulting from the oppressive legal and home-care contexts. The latter resulted in argumentation, which in itself, is actually welcomed (Habermas, 1984) as it can lead to uncovering layers of understanding otherwise unavailable. Although transcription of audiotapes was challenged by these passionate discussions, and participants were fatigued by the end of the three-hour focus group,

overwhelmingly participants' comments suggest they were grateful to have had the opportunity to share their experiences and have their voices heard.

In conclusion, in Ontario, multiple efforts are made at the provincial level to address OAM by dedicated practitioners. This study does not negate those efforts; it instead asks us to consider that any action, without changing the contexts within which these actions occur, will result in the same outcomes. Therefore, continuing to provide education in Ontario, without addressing the non-legislative approach to OAM, and not recognizing the risk for older adults with progressive dementia, will maintain the current stagnation in this field. There are important policy-research-practice gaps in OAM and dementia in this province. The experience of front-line practitioners in Ontario has never been compared to what practitioners experience in other Canadian provinces that have adult protective legislation. This type of research is warranted. Organizations are expected to provide policy guidelines for their employees but they do not have provincial government guidance. Front-line practitioners in this province, who have the distressing privilege of witnessing OAM behind the closed doors of the home, and struggle unsuccessfully to eradicate it within the current provincial contexts, urge us all to consider their realities as an incipient point for policy change. The cases of OAM shared by these practitioner participants have thus far been invisible to policy makers: they have not progressed enough to be captured in police statistics on reported crime, and are not reflected in provincial prevalence studies where older adults with cognitive impairment are excluded. These cases of OAM can therefore only be revealed by understanding the experiences of practitioners in the home, dedicated to the older adults they serve.

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Table 1. Interview participants-Phase I

Identifier	Rural/Urban/Northern or combination	Discipline
NurU1	Urban	Nursing
NurU2	Urban	Nursing
SWU3	Urban	Social work
NurRUN4	Rural/Urban/Northern	Nursing
GerRUN5	Rural/Urban/Northern	Gerontology
NurRN6	Rural/Northern	Nursing
RtRUN7	Rural/Urban/Northern	Recreational therapy
NurUN8	Urban/Northern	Nursing
GerR9	Rural	Gerontology
NurR10	Rural	Nursing
NurUN11	Urban/Northern	Nursing
NurUN12	Urban/Northern	Nursing
NurRN13	Rural/Northern	Nursing
NurRN14	Rural/Northern	Nursing
NurRN15	Rural/Northern	Nursing
SWRN16	Rural/Northern	Social work
SWRUN17	Rural/Urban/Northern	Social work
NurUN18	Urban/Northern	Nursing
RtUN19	Urban/Northern	Recreational therapy
NurRUN20	Rural/Urban/Northern	Nursing
SWU21	Urban	Psychology
NurUN22	Urban/Northern	Nursing
RtUN23	Urban/Northern	Recreational therapy
NurR24	Rural	Nursing
SWRUN25	Rural/Urban/Northern	Social work
NurU26	Urban	Nursing
NurU27	Urban	Nursing
GerU28	Urban	Gerontology

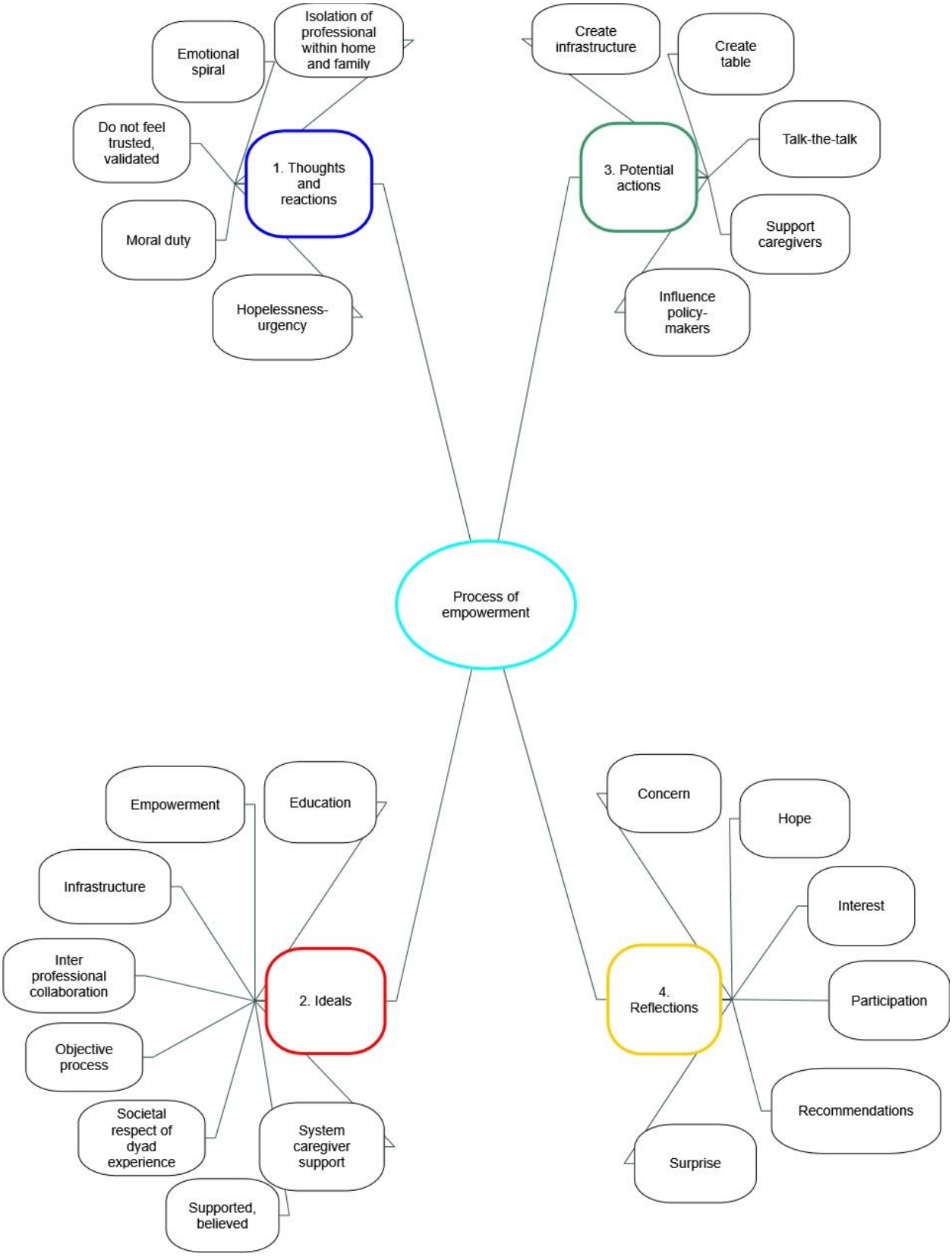
Table 2. Inquiry Focus Groups

Identifier	Rural/Urban/Northern or combination	*n*=29	Years of experience	Disciplines represented
FGIIRUN1	Rural/Urban/Northern	9	6-22	Nursing, Criminology, Psychogeriatric, Domestic abuse, Social work, Gerontology
FGIIR2	Rural	4	10-35	Nursing, Social work, Gerontology, Domestic abuse
FGIIRN3	Rural/Northern	6	5-31	Criminology, Gerontology, Nursing, Business administration
FGIIU4	Urban	3	10-20	Social work, Criminology
FGIIU5	Urban	7	1-42	Social work, Health, Gerontology, Nursing, Corrections

Table 3. Action Focus Groups

Identifier	Rural/Urban/Northern or combination	*n*=31	Years of experience	Disciplines represented
FGIIIU1	Urban	9	1-30	Nursing, Criminology, Psychogeriatric, Social work, Gerontology, Corrections
FGIIIRN2	Rural/Northern	5	9-31	Criminology, Gerontology, Nursing, Recreational therapy, Social work
FGIIIRUN3	Rural/Urban/Northern	5	5-25	Nursing, Criminology, Gerontology, Domestic abuse
FGIIIUN4	Urban/Northern	12	4-36	Nursing, Business administration, Domestic abuse, Recreational therapy, Social work

Appendix 1-Coding Framework-Need for Empowerment



Chapter 5: Discussion and Conclusion

This final chapter offers a synthesis of the three articles and the overall project aims, connecting the experience of lack of professional agency, the oppressive contexts within which it occurred, and the need for empowerment. Figure 1 is again offered to illustrate how these three key themes were foundational to the actions that participants chose to empower themselves, and to influence policy change and practice. The answers to each research sub-question will be offered and discussed within the existing literature on OAM, dementia, and professional practice. Emergent cross-cutting themes and concepts are explored. Limitations will thereafter be discussed as well as recommendations for policy, research, and practice.

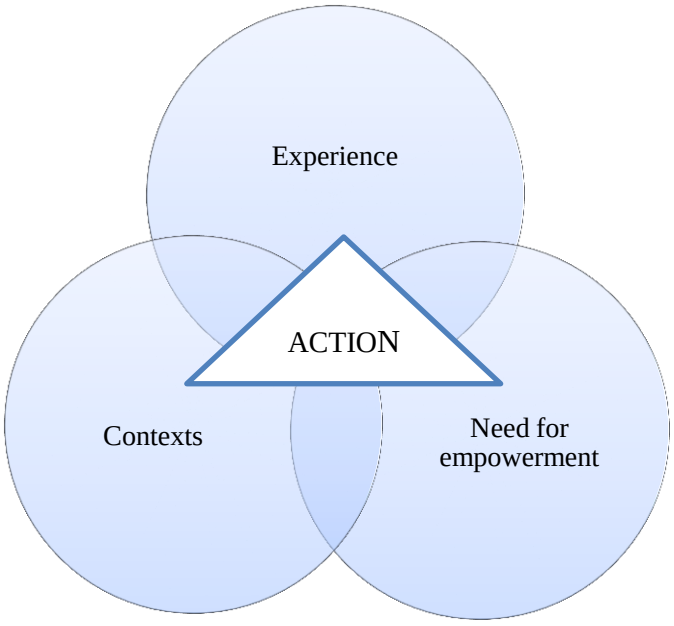


Figure 1: Knowledge-informed Action

Lack of Professional Agency

This study first aimed to understand how practitioners experienced professional agency in cases of OAM and dementia. The reader is reminded of the definition of professional agency: an "emergent, affective, and cognitive process that permits us to respond to our situations in meaningful ways…(it) points to the ethical and political implications of human action… (and)

highlights the ethical call to respond to the needs of the other" (Frie, 2011, p. 341). These notions are congruent with Habermas's (1976) concept of moral consciousness and therefore pertinent when speaking of what practitioners perceived as being meaningful intervention in cases of mistreatment of an at-risk older adult with dementia. This concept was chosen as it: reflects the embeddedness of one's experience within contexts that people do not create, nor do they control; addresses the ethical responsibility of these practitioners and possible obstacles; speaks to one's capacity to act; and offers the potential for change. It is therefore congruent with CST (Habermas, 1971, 1976) in that humans, if given the opportunity to reflect on their situation, realize their capacity to change their contexts.

Through this research, I sought to address a research-policy-practice gap where studies have repeatedly concluded that practitioners are frequently faced with OAM but may not act (Fulmer et al., 2005; Kahan & Paris, 2003; Lachs & Pillemer, 2004; Ortmann, Fechner, Bajanowski, & Brinkmann, 2001). This lack of action is most frequently operationalized in research as a lack of reporting the OAM to authorities as is the obligation in American states. All too commonly, practitioners in these studies are portrayed as lacking knowledge and negative patient outcomes are attributed to them: "since many nurses and social workers …lack the appropriate knowledge and skills…older patients are not getting the screening that might detect (OAM) and subsequent care planning for resolution" (Fulmer et al., 2002, p. 59). Literature will then adopt these findings, regardless of context, and propose the narrative that practitioners are not only professionally responsible to protect the older adult but that they have the power to do so (Harbison, 1999; Phelan, 2008). Those dominant beliefs then become foundational to guidance documents, and, despite the absence of professional and legal obligation to intervene in Ontario, as well as a lack of reporting infrastructure, the tacit expectation is that practitioners will and can intervene in these cases. Such dominant discourse must be challenged for social and political change to occur (Frie, 2011, p. 348).

The cases of OAM shared by participants in this study were complicated by dementia, occurred behind closed doors, were perceived as the practitioners' responsibility, and most often resulted in unfavourable outcomes. The study revealed a complex experience, far surpassing that of lack of knowledge or unwillingness to intervene, where practitioners could not control OAM outcomes. When asked about components of professional agency, such as control in cases, meaningful actions for the well-being of the other, capacity to change outcomes, and meeting their personal expectations of moral and professional duty, overwhelmingly, professional agency was strongly lacking. When the practitioner was able to secure placement in long-term care, maintain access of services to the home in order to supervise for any escalation services, or was able to trust their intuition when OAM concerns were confirmed, a glimmer of professional agency was realised. Nevertheless, they primarily felt powerless to influence outcome in these cases and struggled with being unable to prevent the impending crisis.

Confronted by this vulnerability and inability to practice their socialized role, these practitioners could not respect their own moral consciousness amplified by concerns about human dignity (Habermas, 1976). This experience has been described by workers in child protection when attempting to choose between equally negative outcomes, the necessity but inability to act, the consideration of both the parent and the child, the inability to respect one's own values and the "messiness of day-to-day practice" (Houston, 2003, p. 62). The similarities with OAM are numerous. For some, cases had been morally distressing, an experience previously described with nurses prevented from protecting their at-risk patients within powerful societal structures (Corley, 2002). Some participants described a sense of failing to protect mistreated older adults, findings that have been reported elsewhere (Bergeron, 1999; Dong, 2012).

Practitioners are moral service providers and there is no recognition of their need to intervene in accordance with their socialized professional role, their distress of being unable to

prevent deterioration and the possible personal and professional impact of witnessing but having to tolerate the suffering of OAM. In focus groups, the opportunity to discuss these cases helped address some regret as participant colleagues shared similar experiences, demonstrating empathetic regard towards each other. Participants verbalized hope for greater empowerment with their next cases, changes to the Ontario socio-legal landscape, and the desire to achieve different outcomes for the older adults in their care.

Beliefs, Understandings, and Motives

Participants' actions were guided by their underlying beliefs about OAM, dementia and caregiving, their understandings of pertinent legislation, and their motives to either protect the mistreated older adult or permit them to remain at risk.

Dementia and risks. There is no doubt that dementia increases risks for OAM (Choi & Mayer, 2000; O'Connor & Donnelly, 2009). Participants urged for the recognition of the increased risks that older adults with dementia face stressing that not all older adults are able to choose to remain in a situation of mistreatment. They clearly understood that, in Ontario, older adults who are capable of understanding the mistreatment and appreciating its consequences, are free to decide to accept it or not. However, it was in practice, with older adults with dementia, that a binary decision was difficult. Their descriptions of the characteristics of the mistreated older adults in their care revealed grave concerns in the middle stage of dementia: a greater decline in cognitive and functional abilities with some possible fragments of awareness; lack of insight, and behavioural and psychological symptoms which typically increase in this second stage of dementia (Alzheimer Society of Canada, 2010a). Hall (2006) refers to this stage as a grey zone of not yet being incapable as per the law but more at-risk. Eventually, when the late stage of dementia was reached, and the individual was perhaps bedridden and requiring 24-hour care, incapacity was now clear as per the law, and the mistreatment usually ceased as a crisis of hospitalization or crisis placement in long-term care was reached. A recent systematic review has

again confirmed the increased risks of dementia for OAM (Fang & Yan, 2018) and some researchers have begun theorizing on OAM models specific to cognitive impairment (Mosqueda et al., 2016) including the risk of caregiver burden which was previously refuted but without consideration of stages of the illness (Gainey & Payne, 2006). Such knowledge development is crucial to the recognition that, for older adults with dementia, risks are different than for those without cognitive impairment and these risks may change as the dementia progresses. However, in this province, there doesn't appear to be a recognition of these risks in guidance documents for practitioners. For example, the Registered Nurses Association of Ontario (2014), leaders in evidence-based practice, elaborated Best Practice Guidelines for OAM. Unfortunately, guidance did not address cognitive deficit, was primarily focused on the institutional context where OAM legislation does exist in Ontario, and despite being a provincial organization, the provided legal guidance took a general Canadian lens versus an individual provincial one.

A change of paradigm, one that separates risk from chronological age, could lead to finding common ground between two competing values: that of protecting the autonomy of older adults (Advocacy Centre for the Elderly [ACE], 2016), and of protecting their right to safety (Ontario Human Rights Commission, 2001). Participants felt that the pendulum in this province swayed too much towards autonomy and stressed that dementia rendered older adults at-risk to OAM. This practitioner belief of autonomy trumping protection is not new in the field of OAM (Bergeron, 1999; Mixson, 1995).

Responsibility related to capacity. Capacity assessment was possibly the most nuanced aspect of these cases. In Ontario, there are two very similar expressions which hold very different meanings: capacity assessments and evaluations of capacity to consent. The first process, a capacity assessment, is carried out by specialized 'capacity assessors' of one's capacity to manage property or personal care under the *Substitute Decisions Act, 1992* (Government of Ontario, 2019a). The second process, an evaluation of capacity to consent to

treatment, more specifically admission to long-term care and personal assistive services, is performed by health care practitioners who are considered 'capacity evaluators' (*Health Care Consent Act [HCCA], 1996)* (Government of Ontario, 2018a; Law Commission of Ontario [LCO], 2015, p. 6). The first assessment, based on a consumer choice model, is expensive and must be paid, in most cases, by a family member, the possible perpetrator, while the second evaluation is performed by practitioners. These differences represent crucial barriers to intervention in these cases of OAM, because families would not necessarily pay for the capacity assessment, which as per participants, ranged in their geographical regions from $700-1500, and, very importantly, legal institutions did not accept health care practitioners' evaluation of capacity. Within this structure, practitioners' 'evaluation of concerns' were not validated and the LCO (2015) acknowledges that "these various mechanisms for assessing capacity overlap and interact in complicated and sometimes confusing ways" (p. 6).

To evaluate if an older adult was capable of understanding the mistreatment and was therefore free to remain in that situation, practitioners followed the HCCA. However, the Act failed to assist practitioners with the complexity of cases of OAM and dementia and this, despite practitioners repeatedly following consent and capacity training. When speaking of their cases of incapacity and dementia, some practitioners whispered, possibly because they were unsure, or they were protecting themselves from verbalizing a forbidden conclusion. They were aware that a finding of incapacity was frowned upon by a legislative imperative to assume capacity, the dominant ideology of preserving older adult autonomy, and their experiences of powerlessness when their capacity evaluations were not recognized within the powerful legal structures.

The legal system does not seem prepared to acknowledge these flaws. O'Connor & Donnelly (2009), in explaining Ontario capacity law, reproaches practitioners for making decisions about capacity based on the notion of tolerable risk where "health professionals' assessment of the situation rather than the person's actual ability to choose often guide decision-

making about capacity" (p. 111). Likewise, participants felt that the legal system did not understand the challenges with capacity assessments in practice, speaking, when referring to the legal system, of "us versus them". Indeed, Hall (2009a) clarifies that capacity is a legal concept and that, while medical evidence is important, it is simply evidence "and not in itself conclusive" (p. 121). She continues to explain decision-making and the law in Canada, stating that the law does not intrude into private life and that "the elimination of risk has never been the law's project" (p. 120). In that sense, the law's legitimate role is incongruent with the 'project' of helping professions such as nurses, social workers, and police officers, who view their legitimate role as one of risk reduction or elimination. This difference is of great concern, primarily because it is the legal institution that holds the power to intervene in these cases, but yet, it does not perceive it as their role.

Hall (2009a) does address a legal concept of interest to this discussion: the doctrine of undue influence by which the law will consider the situational vulnerability of the individual, "by reason of the power dynamics inherent in the relationship itself" (p. 125). Doing so allows the law "to 'see' vulnerability outside of incapacity as legally relevant" (p. 128). The concept of undue influence, to the best of my knowledge, does not appear in Ontario guidance documents for practitioners. Perhaps there is some common ground to be found between this legal concept and what practitioners also 'see' in the relationship of power between the older adults with dementia and mistreating caregivers that they visit in their homes and the escalation of mistreatment that they must witness before a crisis occurs. Perhaps the concerns of practitioners are not simply their inability to tolerate risks. However, until such common ground is found, responsibility for these case outcomes once again returns to lie with practitioners.

Dementia and OAM as threats to personhood. The Alzheimer Society of Canada (2010a) lists dementia, illness and hospitalization, amongst others, as threats to personhood. I believe that OAM is also a threat to personhood. When those closest to the older adult,

representing primary attachments, fail to provide a sense of security, comfort, inclusion, and identity, personhood cannot be maintained (Kitwood, 1997a). Participants described the 'suffering' of the mistreated older adults in their care, and despite fluctuating cognitive ability, they witnessed fear and sadness. They attempted to understand the "subjective experience of dementia" (Kitwood, 1997a, p. 13), the emotions older adults with dementia experience (Petty, Harvey, Griffiths, Coleston, & Dening, 2018), and recognized the relational importance of family to these older adults even when they were mistreating them (O'Connor & Donnelly, 2009). Hence, participants respected the concept of personhood with the belief of the accompanying rights to safety and dignity as a person (Boddington & Featherstone, 2018). However, they deplored the societal disregard for older adults with dementia and the lack of personhood was believed to perpetuate OAM normalization. When a person is "no longer deemed to be a person… (they are) thus not worthy of consideration (Kitwood, 1997a, p. 13). Although the personhood literature also speaks of the dangers of infantilization and right to autonomy (Kitwood, 1997b), the concept should not be used to justify leaving older adults with dementia in mistreatment situations.

Contextual influences: Predominant Ideologies and Dominant Structures

Participants' experiences were further influenced by ideologies of risk and caregiving responsibility within the home care structure, opposing conceptions of ageism, geographical vulnerabilities and legal complexity.

Risk in the home. Within the home, some practitioners with home health, social services, and law enforcement held opposing perceptions of risk: for some it was considered a danger, and for others, an older adult's right. The root of these differences partially lies in the ideologies within one's organizational work culture. In provincial home care documents, the term risk appears frequently traditionally having three different connotations: the risk of hospitalization, the imminence of placement in long-term care, or one's right to choose to live at risk (Ministry

of Health and Long-Term Care, 2009). Ceci & Purkis (2009) propose that Canadian home care practitioners have had to adapt to risks intrinsic to the home context and must tolerate them. This could however lead to a normalization of risk within the home context, and as previously seen, some could incorrectly use the concept of personhood to uphold the dominant rhetoric of "right to live at-risk" in the context of provincial home care services.

Persisting in current provincial documents (Sinha et al., 2016), this ideological influence on beliefs and actions was evident in the language and interventions of some practitioners from one organization in particular where some OAM cases, even with clearly at-risk and incapable older adults being subjected to mistreatment, were disregarded on the principle that one has the right to choose to remain at risk. Language is therefore an important influence, because if perceived to be a "normative claim", it will prevail, control and devalue those who do not hold the same values (Boychuk Duchscher, 1999; Martin, 1998, p. 153; Ruangjiratain & Kendall, 1998). As this particular organization influenced home care services, their interventions or lack thereof in cases of OAM influenced outcomes. This discourse was not replicated by participants from most other organizations who, when speaking of risk, were referring to the danger of mistreatment of an older adult with dementia, of its escalation, or of not being able to end it. Interestingly, in many of the regions, the membership of these practitioners on community OAM groups had dwindled. In regard to the study, recruitment from this particular organization was challenging and retention of most of these participants was not successful into the second phase of the study. Those who did continue participating into Phase II encountered some harsh comments from other participants for perceived limited service allotments or closing files without consideration of risks. In these cases, the differing perceptions of risk, as a danger or as a right, were revealed during discussions.

For others, the home context represented a danger that they could not control. They faced the always present threat of cancellation of services by a substitute decision maker. Gatekeeper

to the home, family caregivers did refuse services placing the most isolated and at-risk older adults who are shielded by their abuser at a far greater risk (Fitzsimons, Hagemeister, & Braun, 2011; Lachs & Pillemer, 2004; MacKay-Barr & Csiernik, 2012; Weeks, Richards, Nilsson, Kozma, & Bryanton, 2005). The home context as etiology of increased risk of OAM is an overlooked area of family violence (Lowenstein, 2010), and is not acknowledged in some Ontario legal literature. For example, ACE (2016), within their mandate to protect the autonomy of older adults in Ontario, purports that adult protective legislation is not required for older adults living in the community but is justified in long-term care or residential care institutions:

> Dependence on the operators of these homes for assistance with the activities of daily living, as well as the insular nature of these homes, render residents more vulnerable to abuse or neglect. This distinguishes these settings from other places where older adults may reside. In this context, mandatory reporting of abuse to the prescribed regulatory authority is an appropriate protection. (p. 9)

To decrease the isolation of these dyads, practitioners felt successful when at least providing a minimal service plan to supervise the home for any escalation. Abiding by privacy legislation, only when risk became serious enough and imminent could they share the secret of what was occurring behind these closed doors. Until this occurred, they held this burden, and socialized to protect their patients, they felt helpless. This notion has not been addressed in the literature.

Caregiving responsibility: Family or state. In the OAM cases described, participants expressed concern about societal expectations of family caregiving regardless of fit and without recognition of caregiver burden. Buckwalter, Campbell, Gerdner, & Garand (1996) similarly explain that caregivers remain "invisible to traditional systems of care" (p. 261). However, caregiving must be acknowledged as providing "an especially fertile ground" creating the context where care interactions become triggers for OAM (Anetzberger, 2000, p. 48). Specific

aspects of caregiving are significantly associated with severe OAM including living together, providing more hours of care, severity of cognitive impairment, caregiver burden, caregiver depression, and insufficient formal support (Compton, Flanagan, & Gregg, 1997; Cooper et al., 2006; Coyne, Reichman, & Berbig, 1993; Homer & Gilleard, 1990; Lachs, Williams, O'Brien, Hurst, & Horwitz, 1997; Lee, 2008; Lowenstein, 2010; Paveza et al.,1992; Pillemer & Suitor, 1992; Wiglesworth et al., 2010).

Instead of recognizing this potential for OAM, a systemic overreliance on family caregivers is a reality of the current home care system which has suffered numerous reductions (National Advisory Council on Aging, 2006). As a result, caregivers are left with increased responsibilities within a health care system that primarily considers caregiving as a family responsibility (Allan, 2002; Dauvergne, 2003). Using the CST lens, practitioners in this study engaged in dialectic discussions about the contradictions and subsequent policy-practice gap between governmental rhetoric of providing home care permitting older adults to safely age in place in their homes, and the opposing reality witnessed in practice. Participants felt that governmental promises to increase caregiver support have not materialized, despite influential documents demonstrating the projected prevalence of dementia and subsequent rise in informal caregiving hours (Alzheimer Society of Canada, 2010a). Although hopeful for provincial and national dementia strategies, participants doubted that these would amount to increased caregiver support. As representatives of this health and social services system, they perceived themselves as failing older adult/caregiver dyads as they were unable to relieve the caregiver burden viewed as a correctable contributor to OAM. The dependence of the home care system on informal caregivers, previously noted as a concern (Canadian Institute for Health Information [CIHI], August 2010a), was perceived to be so large that it was probably insurmountable. Participants also considered themselves as advocates for burdened informal caregivers who mistreat because

of burden. It was felt that the focus on promoting the independence and health of older adults dimmed the attention on more challenging problems such as OAM.

Some grey literature has proposed that the ideal response to OAM is to provide supports and services required by older adults to "avoid becoming dependent on their family caregivers" (LCO, 2012, p. 104). This negates the reality of dementia care where a progressive deterioration will render dependence on family, for those remaining in the home context, an eventual outcome.

For OAM to be recognized as a public problem requiring a policy or legal response, it must be extracted from the family private realm. However, given the importance of the institution of family, Brandl & Raymond (2012) explain that OAM occurring in the domestic context is rendered invisible and, consequently, remains a family problem rather than a societal one. The ideology of family caregiving can be dangerous as it neglects the cruel reality that OAM does actually occur within families (Anetzberger, 2000; Carp, 2000; Norris, Fancey, Power, & Ross, 2013; Statistics Canada, December 2018), especially due to the increasing risks related to the "instability of contemporary intimate relationships" in Canadian families (Brozowski & Hall, 2004, p. 68). However, instead of considering OAM as a social problem, some literature appears to support the ideology of familialism where choice, family privacy, autonomy, and independence are favored (Harbison, 1999; Harbison, Coughlan, Karabanow and VanderPlaat, 2005). Without deconstructing this powerful ideology, society continues to view families as protectors from OAM **(**Human Resources and Social Development Canada, 2008) and certainly not as perpetrators as studies have revealed (Choi & Mayer, 2000; Lachs et al., 1997; National Research Council [NRC], 2003). Such deep-seated beliefs were distressing for practitioners as family caregivers, even those who admitted to OAM and described entitlement due to their perceived caregiving sacrifice, were trusted under societal assumptions of simply doing their best. Other than placement in long-term care, there were no other options for mistreated older adults with dementia as family caregiving is such a strong societal expectation.

This highlights the added complexity of OAM perpetrated by a family member who serves a "worthwhile function" in the care of the older adult that cannot be provided otherwise within the current home care system, a notion previously addressed by APS workers (Bergeron, 1999, p. 104). This traditional view also relegates all responsibility for protection from a mistreating family member to the practitioner in the home while absolving society of any such responsibility. Biggs (1996) eloquently explains that "the state has located elder abuse firmly within the family or, failing that, within the victim's own home" (p. 67). This ideology was consequently oppressive to practitioners who, despite not agreeing with these social norms, held a perceived responsibility to stop the mistreatment.

The impact of opposing conceptions of ageism. In the OAM literature, the term "ageism" appears frequently although it carries different connotations. The first representation, congruent with that of this study's participants, presents ageism as a root source of OAM. Erlingsson, Carlson, & Saveman (2006) have described how OAM might "be tacitly sanctioned by society" (p. 151) that marginalizes and lacks respect for older adults and where societal systems "contribute to the genesis of abusive behaviors" (p.157). Similarly, Biggs & Haapala (2013) add that "ageism can be thought of as an assumptive reality permissive of certain social actitivies (Phillips, 2010), with age discrimination as a condition of society and mistreatment as its behavioral consequence" (p. 1299). Practitioners did address such societal level ageism which contributed to devaluing older adults, especially those with dementia. They explained how society appears to accept the mistreatment of those with dementia where deterioration is normalized. Parallels were drawn with other at-risk groups such as children where, confinement to a basement, or lack of food in the home, would certainly trigger intervention. However, such did not occur in their cases of OAM where confinement, weight loss, and withholding human interaction were common occurrences. Therefore, not providing the necessities of life, such as food and warmth, seemed to be acceptable to society who perceived that caregivers were simply

doing their best in a very challenging situation. Similarly, Blundo & Bullington (2007) have proposed that OAM has "not been viewed as seriously as child abuse because of the emotional sensibilities attached to child abuse" (p. 173).

Practitioners expressed having to tolerate ageism by other family and community members. Despite their will to intervene, but unable to change this dominant ideology, some believed that they had failed and were therefore part of the societal problem. American Adult protective service workers have similarly described a sense of failure with OAM cases (Bergeron, 1999).

However, there is a second presentation of "ageism" that is detrimental to OAM efforts. Some researchers have accused practitioners of ageism, of abusing their power over older adults, and of self-protection in OAM cases (LCO, 2015; Phelan, 2008). A conceptual definition of ageism, offered by Iversen, Larsen, & Solem (2009), which incorporates the three components of stereotypes (cognitive), prejudices (affective), and discrimination (behavioral), is helpful to organize this powerful narrative. In this very strong literature, practitioners are accused of holding stereotypes that all older adults are weak, of being prejudiced as they pity the older adults in their care, of holding an aversion to aging and disregard for older adults, and that adult protective legislation would be discriminatory based on age. Furthermore, accusations of lack of reporting as a cause for poor statistics in OAM, of not taking the lead in cases, and of providing poor care as "an important catalyst" to OAM, have all been made against some categories of practitioners (Phelan, 2009, p. 116). The literature has historically blamed practitioners for failing to detect, failing to report OAM, and of instinctively and uncritically unloading caregiving to mistreating families (Kosberg, 1988). Finally, language such as the "guidance and domination of service practitioners" (Harbison et al., 2005, p. 3), the use of "draconian measures of interventions", (p. 6) and judgements of prompt reporting by practitioners to adult protective workers as being "less concerned about older people's rights and wishes" (p. 242) reflects a

powerful discourse of blame towards service practitioners. Instead of recognizing that not all older adults can be empowered to protect themselves, accusations of infantilizing older adults are brought against those advocating for adult protective legislation. Powerful organisations in Ontario are strongly opposed to language such as frail or vulnerable. While recognizing that "at least some older adults are at risk of significantly negative outcomes" (LCO, 2012, p. 54), 'vulnerability' is equated with 'paternalism', 'compassionate ageism' and "coercive responses" (LCO, 2012, p. 56). Furthermore, attempted government attempts to introduce protective legislation have been referred to as "overzealousness to protect so-called at-risk older adults" (ACE, 2008, p. 5).

This narrative is then accepted by others, appearing in provincial resources on OAM or literature, and serving as an ideology infecting the discourse on OAM (Habermas, 1976). Such messages are oppressive, negating the experience of those who accompany these dyads through the mistreatment and certainly persevere despite numerous obstacles. This study permitted practitioners' voices to be heard. It revealed that, unlike the dominant view in the literature, practitioners were very knowledgeable about OAM and dementia. They had experienced many cases, were resourceful and attempted every available intervention. They were driven by personal commitment and professional ethic. In fact, participants regarded as ageist the province's refusal to consider protective legislation for older adults when all other groups at risk in Ontario have legislation specific to them.

Geographical vulnerabilities. Those practitioners who lived in or serviced a rural or northern area faced additional challenges. They spoke of isolation of the dyad and of themselves as some were the only practitioner from their organization in the area. A lack of human resources rendered increased supervision by formal services in the home impossible. Some practitioners who serviced rural communities further north functioned in physical isolation, only able to access a team by telephone. One of these practitioners described abandonment by the health and

legal systems as practitioners were left to deal with these cases alone. Likewise, Vandsburger, Curtis, & Imbody (2012), have described constraints to rural care resulting from fiscal cuts to services. They link these factors to an inability to meet professional standards, as well as guilt and stress, and feeling that it is "inhumane to compromise assistance to an at-risk population" (p. 370). Although practitioners longed for an interdisciplinary community response, it was increasingly challenging in northern rural areas where human resources and community services were greatly lacking.

Inequity in regard to access to services and options for older mistreated adults in rural and northern communities has previously been shared by stakeholders during ministerial round tables with the Minister of State for Seniors (Human Resources and Skills Development Canada [HRSDC], 2012). More specifically, rural concerns such as lack of supervisory support, interdisciplinary team consultation, expertise, community resources and education have been highlighted (Federal/Provincial/Territorial Safety and Security for Seniors Working Group, 2007). Over the course of this study, similar concerns were revealed. Day programs were severely lacking in some regions, either not appropriate for older adults with cognitive impairment or incontinence, or not existing and requiring travel to programs over one hour away. Practitioners reported longer wait list for long-term care beds in their communities, including crisis placement, a necessary option in cases of OAM by a family caregiver. Another particular concern was the loss of the community's senior liaison police officer who served a case management function, with replacement by a lay person coordinator. This loss was devastating to practitioners who had relied on this person's positional power to investigate and intervene when the risk in the home became intolerable. The LCO (2012) refers to this position as one that could assist with OAM investigations with "high profile cases" (p. 176) that benefited from specialized elder abuse units. It is interesting that the cases described within this document closely resemble cases described by these study participants; complex cases that the latter had to

manage alone without such specialized support. This loss, described by most Northeastern Ontario regions in this study, was initially thought to be a provincial phenomenon. However, it is unknown if larger cities have maintained this specialized resource. A study conducted within a large urban region of Southeastern Ontario described the activity of a strong unit of police officers strictly dedicated to OAM (Ha & Code, 2013). A recent view of this city's police website speaks of a current team dedicated to OAM. The important contribution of these specialized police units was also raised by Beaulieu, Coté, & Diaz (2017) within the city of Montréal, Québec. These specialized officers, considered "champions" are able to assume a "leadership role" (p. 410). Given their pivotal role in large cities, and lack in Northeastern Ontario, an inquiry into this possible northern and rural inequity is warranted.

Assumptions that families, friends, and neighbours can compensate for rural formal services is a dangerous expectation when a family member is mistreating the older adult (Harbison et al., 2005). In this study, rural practitioners raised concern regarding the privacy surrounding some cases, the isolation of the dyad from both formal and informal networks, and the danger of downloading care responsibilities to rural families when the OAM is occurring within them. Given these findings, and the higher prevalence of family violence in rural Canada (Statistics Canada, December 2018), caution must be used when labeling rural communities and practitioners as resilient, psychologically hardy, independent, or self-reliant (Keating, 1991; Podnieks, 1993; Vandsburger et al., 2012). The practitioners in this study certainly were committed, strong, and perseverant for the older adults/caregivers in their care; however, the socio-political and geographical contextual limitations imposed upon them were detrimental to their professional agency.

Legal complexity. As health care and social service practitioners, working within the complex and multifaceted legal context demanded extensive legal knowledge regarding criminal law, the home context, capacity assessment and evaluation, substitute decision law, privacy

legislation, police case law, and mental health law. Despite their breadth of knowledge and experience, the lack of legislation and little guidance nor support to navigate this system left practitioners feeling perplexed and at-risk. These practitioners are not the first to express challenges in a socio-legal context without adult protective legislation. In addressing a similar context in Sweden, Saveman, Hallberg, and Norberg (1996) wrote that this absence:

> …may contribute to the neutral attempt of the DNs (district nurses). Lack of legal duties can be interpreted to mean that abuse of the elderly is not of public interest and thereby is implicitly accepted by the community as well as by professionals (p. 231)

As detailed in the previous chapters, in Ontario, most other populations considered to be at-risk, including victims of intimate partner violence, vulnerable persons that have been disabled since birth, older adults in long-term care or residential institutions, and children, are all protected under their own specific provincial legislation. One piece of legislation that could be pertinent to OAM organizational guidance was the *Home Care and Community Services Act, 1994* (Government of Ontario, 2019b). This act states that agencies "shall develop and implement a plan for preventing, recognizing and addressing physical, mental and financial abuse of persons who receive community services provided by the agency or purchased by the agency from other service providers" (Government of Ontario, 2019b, section 26.(1)). However, no further information could be located about this plan and it is therefore unclear what its application has been in Ontario and if it refers to OAM perpetrated by service providers, family, or strangers. Furthermore, none of the participants from health and social services who would fall under this guidance were aware of any organizational plan, policy or procedure.

Therefore, without specific older adult legislation, practitioners in this province must be cognizant of five related laws, the first being the *Criminal Code of Canada* (Government of Canada, 2018) which is to be used when a crime has been committed against an older adult

(ACE, 2016). However, practitioners described its numerous limitations in their practice and were bewildered that additional protective legislation did not exist for older adults living in their home as it does for other at-risk populations. Similarly, Beaulieu and Leclerc (2006) raised that "other types of crimes (…) are more severely punished than mistreatment towards the elderly" (p. 182). Despite these clear inequities, practitioners spoke cautiously, possibly feeling unable to critique the powerful hierarchy that is the law (Sumner, 2010a). In providing care, the primary barrier resulting from this absence was the Code's inability to authorize the extraction of a mistreated older adult from the home context to a place of safety, as opposed to legislation in place authorizing protection for other at-risk populations.

Providing care within the home required knowledge about two further pieces: requirements of sufficient evidence to warrant police to enter the home because, unlike other at-risk populations, there is no legislation granting authority to cross that barrier for older adults; and the *Mental Health Act, 1990 [OMHA]* (Government of Ontario, 2015), which was the only means to authorize the removal of the mistreated older adult from the home for their safety.

Nevertheless, the use of the *OMHA* was considered highly problematic for individuals with dementia because the language of the Act, which speaks to threatening or attempting to cause bodily harm to oneself, behaving violently towards another, or lacking competence to care for oneself, language that blames the victim and lacks pertinence when the risk in the home stems from the mistreating caregiver and not the older adult's mental health. Again, drawing comparisons with other at-risk populations, practitioners indicated how the language is clearly inappropriate for neither abused children nor victims of intimate partner violence, but yet, there exists no other options for older adults.

Next, an understanding of the *Substitute Decisions Act, 1992* (Government of Ontario, 2019a) was required. In many cases, the mistreatment was occurring at the hands of the substitute-decision maker as per the legally established hierarchy which is strongly based on

family ideology: “Ontario laws give preference to family members to act as substitute decision-makers” (LCO, 2015, p. 20). This emphasis is of grave concern when the perpetrator of the mistreatment is a family member or when trying to locate another appropriate family member (Cupitt, 1997). The LCO (2015) acknowledges the risk of “inappropriately allocating responsibility” (p. 5) for decision-making to individuals who may not be well-suited for this role and the necessity of sometimes having to choose the “least bad option” (p. 20).

In Ontario, legal institutions insist that there are mechanisms in place to address OAM of incapable older adults: “where the older adult is incapable, the law has a process by which decisions can be made to protect them from abuse or neglect” (ACE, 2016, p. 12). For example, if concerned that a substitute decision maker was not acting in the best interests of the older adult, practitioners could apply to the Consent and Capacity Board “to determine compliance of (the) substitute with the legislation” (Wahl, 2013, p. 54) and that the Office of the Public Guardian and Trustee [OPGT] has a duty to “investigate any allegation (Wahl, 2013). However, practitioner powerlessness again resulted as the OAM concerns they presented to these institutions failed to provide the level of evidence required to trigger an investigation. For the latter to occur, the practitioner making the complaint must provide “evidence that the victim is incapable of managing property or personal care” (p. 24) and “evidence that serious adverse effects are occurring or may occur as a result” (Wahl, 2013, p. 25). With very few exceptions, after following this strenuous process, most often without positive outcomes, practitioners felt defeated and without professional agency. The LCO (2015) has recognized this “lack of meaningful mechanisms for accountability when misuse is suspected” (p. 14) and that the “court-based adjudicative mechanism under the Substitute Decisions Act has been critiqued as being complex and difficult to navigate” (p. 16). Furthermore, ACE (2008) stated that in many cases, the OPGT has “interpreted its duties very narrowly and does not intervene often enough” and recommended a review to determine if the OPGT is “using their powers appropriately” (p. 35).

However, in 2017, in a review of Ontario laws related to legal capacity, decision-making and guardianship, which promised to address these challenges by strengthening safeguards against abuse by substitute decision makers, the LCO placed the onus on the person creating a power of attorney, to name a "monitor" to oversee the compliance of the substitute decision maker. It is unclear who is to play this role, if this again will reinforce the problematic familial ideology which situates OAM as a 'family' problem, and how this will assist when no such "monitor" was named by the older adult prior to becoming incapable. The LCO (2017) further clarified in this law reform report that the mandate of investigation of the OPGT was reserved for grave violations of statutory rights by substitute decision makers. For their part, the OPGT, which receives "allegations that an adult is mentally incapable of making decisions about their property or personal care, and is at risk of serious harm as a result" (2018, p. 2), reported, for the year 2017-2018, receiving "3,000 allegation calls which is becoming unstainable" (p. 3). Citing aging demographics and the rising rates of dementia in this province, the OPGT has expressed concern about the challenges that lie ahead. CARP (2018) has acknowledged these challenges: "Right now there is no one easy place to report elder abuse, and no clear agency with the responsibility to respond. The Public Guardian and Trustee does its best with its limited mandate and even more limited budget".Thus, despite acknowledgements from Ontario legal institutions of frequent abuses of the mechanisms currently in place to protect mistreated older adults, and the unsustainability of the supports currently in place, practitioners remain unsupported in their struggle to end OAM occurring in the home.

The CST lens of this study required challenging taken-for-granted notions in order to seek alternative ways of addressing a phenomenon. As per these findings, the current provincial system, despite everyone's efforts, is not able to protect older adults with dementia who are mistreated within their homes. This message will not be welcomed by many in Ontario who endeavor towards older adult autonomy (ACE, 2016; LCO, 2012). Although certainly

appropriate for the general older adult population, goals of independence, autonomy, and empowerment are not realistic for older adults with progressive cognitive impairment who cannot safely remain in their homes without caregiver assistance.

Does adult protective legislation positively impact case outcomes? While the original purpose of adult protective legislation was to guide successful intervention in OAM cases, and more countries are adopting adult protective legislation, legislative models should be based on empirical data (Gordon, 2001). However, empirical data on OAM is severely lacking, not only in Ontario and in Canada, but on an international level (World Health Organisation, 2014). Although many countries have carried out national prevalence studies using the similar random telephone design with cognitively intact older adults that was conducted twice in Canada (McDonald, 2015; Podnieks, Pillemer, Nicholson, Shillington & Frizzel, 1990), these prevalence findings paint an incomplete picture. In this province, other than the police-reported data described in Chapter 1 on violent offences covered under the *Criminal Code of Canada*, and the GSS which provides limited self-reported data on victimization, data on cases of OAM is unavailable. It is not tracked by those health and social service organizations that provide services in the home, because although it is their practitioners who respond to and deal with these cases, there is no organization in Ontario mandated to respond to OAM. Data comparing rates of OAM in those provinces with and without adult protective legislation, as well as pre and post introduction of legislation, could not be located. Given the limited information that was found, it is believed that where there is no legislation, this data is not tracked at all. What follows is the data that could be located from the grey and scientific literature.

Provincial and federal websites were searched and email requests for information had limited success. In Ontario, the OPGT, upon request, did provide their annual reports for the past five years. The OPGT Annual Report for 2013/14 indicated that 238 screening and field investigations into allegations of harm, self-neglect or abuse were conducted, with the

subsequent provision of 18 personal care guardianship clients. No similar numbers are provided in the 2014/15, 2015/16, and 2016/17 reports. Therefore, it is impossible to grasp a historical understanding of how many allegations are recorded, how many allegations are investigated, and how many have resulted in guardianship orders. As previously stated, the 2017/18 report speaks of receiving 3,000 allegation calls but no further numbers are provided. The reader is reminded that, in Ontario, the responsibility to investigate allegations of mistreatment falls specifically onto the PGT. Therefore, there is no other data available as cases dealt with by practitioners, such as the participants in this study, are not tracked as no organisation is mandated to deal with these cases in this province. As eloquently stated by this study's research participants, cases are "picked up in fragments" with OAM not being "anyone's mandate at this time".

In British Columbia, since the introduction of the Adult Guardianship Act (1996), the Public Guardian and Trustee, which receives allegations (of financial mistreatment only), increased its investigations by fifteen percent in 1999-2000 post introduction of the Act. Reviewing reports from 2001/2002 to 2017/2018, the cases in which the BC PGT took protective measures have increased from 21 to 165 cases yearly (all reports are available on the BC PGT website). Therefore, although rates of reports of allegations of financial mistreatment have increased, this data does not indicate how many of these allegations pertain to older adults nor the cases that are dealt with by practitioners mandated to intervene in cases of non-financial mistreatment.

The Act also assigns responsibility for non-financial cases of mistreatment to Designated Agencies in that province. Attempts to locate statistics of cases reported to these agencies resulted in limited success. The BC PGT did provide a report by the Office of the Seniors Advocate of British Columbia (2018) which explains this gap in data: "It is difficult to establish the number of seniors in B.C. who experience abuse, neglect, or self-neglect as there is no central registry of reported incidents, and many seniors and/or families turn to multiple organizations to

seek support" (p. 57). While the PGT received 1540 allegation calls in 2017/18, 778 cases proceeded to investigation. The non-investigation of other cases does not imply OAM was not occurring, but perhaps support by a Designated Agency was deemed more appropriate. At this time, data is "piecemeal" and although the Office of the Seniors Advocate has requested such statistics from each Designated Agency, cases managed by these agencies are not tracked (verbal communication, BC PGT).

> What can be gathered from the Office of the Seniors Advocate report (2018) is that the Seniors Abuse and Information Line (SAIL) received 1,546 calls related to abuse in 2017, a 2% decrease from the previous year; the bc211 helpline received 300 calls related to elder abuse in 2017/18. These calls have been declining, decreasing 8% in 2017/18 and 19% in 2016/17 (p. iii).

Despite these decreases,

> Reported offences against seniors are rising; there was an 11% increase in violent offences and a 1% increase in property offences reported to the RCMP (Royal Canadian Mounted Police), as well as a 20% increase in physical abuse cases and 26% increase in financial abuse cases reported to the Vancouver Police Department (p.iii).

Attempts to reach out to the Prince Edward Island and Nova Scotia provincial government branches responsible to receive allegations of mistreatment were unsuccessful.

In the scientific literature, only two researchers have addressed legislative differences in Canada. Harbison and colleagues (1995), strong opponents of adult protective legislation, did demonstrate that the strong legislation in Nova Scotia, labelled a "Protectionist Regime" by the Canadian Centre for Elder Law [CCEL], (2011a), resulted in a dramatic increase in the number of reported mistreatment cases. However, it was used excessively, specifically for self-neglect cases, to the point of judicial criticism of violation of human rights. More comprehensively, Gordon (2001), in a seminal article, compared issues with the different Canadian models.

Although some legislative changes have occurred since this paper, no further comparative evaluations could be located. Gordon (2011) concluded that there are "few publicly available statistics on which to build even some basic conclusions about the uses (and abuses) of the legislation and policy" (p. 128). He also noted that although "the image of Canadian adult protection legislation in practice may well be badly skewed by the contentious self-neglect cases" of Nova Scotia, "data are not available for other jurisdictions" (p. 129). Therefore, presently, it is impossible to evaluate the different legal regimes in Canada and if these result in positive outcomes for mistreated older adults with dementia. Canadian lawyers Watts & Sandhu (2006) write of this silence on legal discussions about OAM in Canada, referring to this country as "lagging forty years behind" our American neighbours and that "what Canadians deny, through their silence, is that elder abuse and neglect might actually be a crime" (p. 236).

Therefore, in an attempt to understand if adult protective legislation positively impacted rates of OAM, empirical data from other countries with adult protective legislation was sought. In the United States, a seminal study by Jogerst and colleagues (2003) provided data on OAM report rates, investigation rates, substantiation rates, and substantiation ratios from each participating US state. Citing the absence of any previous systematic inquiry of this type, this data was not publicly available despite each state having some type of adult protective legislation. Therefore, the researchers requested data from the administrators of the adult protective programs in each state which differed greatly in regard to mandatory reporting requirement, tracking of reports, if there was a statutory penalty for failing to report, and whether practitioners investigated both child and adult allegations. They then examined whether these dependent variables were influenced by the state's specific statute pertaining to OAM. It was surprising to learn that even in American states, where adult protective legislation exists but statutes differ in each state, case numbers are not necessarily tracked. The study concluded that significantly higher investigation rates and substantiation ratios were found for states that

required mandatory reporting, tracked numbers of reports in their statutes and in which practitioners were solely assigned to OAM cases.

Again in the United States, Daly & Jogerst (2014) next studied the association between investigation rates and the presence of multidisciplinary teams based on states statute obligations. Although only nine of the 50 American states and District of Columbia included such legislative text in their 2008 statutes, the study concluded that, in those states where the statute specifically included legislative text obliging administrators to have these teams, reporting and substantiation rates were higher and investigation rates were significantly higher. Thus, it would appear that infrastructure and legislation do result in revealing OAM cases and in contributing to collaborative efforts to address them. These findings have important implications given the self-driven efforts of practitioners in this province, whose organizations are not mandated to address OAM, but who nevertheless attempt to work together despite significant barriers to collaboration.

One other researcher has lead studies in Japan, where an elder abuse law was enacted in 2006. Nakanishi and colleagues (2009) investigated the impact of the new law on system development by governments in all Japanese municipalities. Their findings demonstrated that the introduction of the law was a significant step in establishing reporting systems (46.2-49.1%) and in increasing awareness of OAM among practitioners (30.7-35.8%). Later, Nakanishi, Nakashima, Sakata, Tsuchiya, & Takizawa (2013), examined the relationship between the development of municipal detection and interventions systems, and the reporting rates of suspected OAM cases, and substantiation rates in municipalities across Japan. Since the introduction of the legislation, the ministry responsible to investigate OAM reported that in 2006, 18,390 reports of suspected OAM in the family setting were received, of which 12,569 cases were substantiated. Those numbers have increased yearly, and in 2010, they reached 25,315 and 16,668 respectively. The study concluded that higher rates of both investigation and

substantiation were significantly associated more staffing assigned to these cases. In some municipalities, where programs focused instead on the development of training resources and training practitioners, education was not significantly associated with rates of reported and substantiated OAM cases.

This section aimed to locate empirical data on the association between adult protective legislation and case resolution. Based on the limited available data, at the provincial, national, and international levels, conclusions cannot be drawn given the complex nature of these sensitive cases and the absence of legislation and tracking. In 2002, the World Health Organization [WHO] called for the enactment of stronger protective laws and policies. In its 2014 report, the WHO noted that only 40% of countries had enacted such laws for OAM. Citing progress made on OAM legislation and infrastructure in some countries, the WHO's key recommendations include the implementation of adult protective legislation in all countries and data tracking to "reveal the true extent of the problem" (p.48). The data provided in this section, although limited, does demonstrate that OAM in the domestic context does certainly exist and can only become visible when legislation is in place to support practitioners in investigation of allegations and the substantiation of cases. Given the rise in police-reported violence towards older adults, the number of cases revealed where tracking occurs, and the association between the presence of adult protective legislation with reporting and substantiation rates, it is imperative that the WHO recommendations are implemented so that OAM occurring in the home setting can be exposed.

Impact of Oppression on Experience

The dominant ideologies and societal structures described above resulted in limiting practitioners' actions in cases of OAM and dementia. Consequently, professional agency was reduced, lateral conflict prevailed as cases could not be resolved, and a historical erosion of participants' perceived power to effectuate change in Ontario was witnessed. As a result, the gap

between research and practice grows and practitioners' experiences with mistreated older adults with dementia remain unacknowledged.

Lack of professional agency. Practitioners described feeling powerless until a crisis occurred, and although surely not intended in the law, the language does not permit early intervention to prevent escalation of OAM. Under the *Substitute Decision Act of 1992*, 'serious adverse effects' are defined as "Loss of a significant part of a person's property, or a person's failure to provide necessities of life for himself or herself or for dependants. Serious illness or injury, or deprivation of liberty or personal security" (Wahl, 2013, p. 22-23). Practitioners carried out the actions offered in provincial legal guidance documents but these were futile: calling police, who, in this study, explained their lack of authority when OAM occurs within a home; the Seniors safety line which referred the case back to the practitioners; the OPGT who did not accept their capacity evaluations or concerns; or ACE who is transparent in all resource material about their guiding mandate to uphold the autonomy of older adults. Placing health and social service practitioners within this complex legal context, without support, was clearly oppressive. At times quite subtle, it was the dominance of the legal expertise that inhibited practitioners from having a different point of view. The use of professional jargon was powerful in silencing practitioners.

Habermas' (1984) concepts of system-world and lifeworld further explain this dominance by the legal system. As a socially dominant structure of the system-world, the legal system exerted power over these participants. Instrumental knowledge of facts and evidence, required to prosecute cases, was deemed more rational and valuable than the participants' moral-practical knowledge (Scheel, Pedersen, & Rosenkrands, 2008). However, this insistence on objective rational thought invalidates the subjective experiences of human beings (Boychuk Duchscher, 1999). This dominance of the practitioners' lifeworld also devalues formal care practitioners. Scheel and colleagues (2008) explain how such dominance is harmful to health care

practitioners, who, by nature of their professional socialization, are moral practitioners. However, they cannot fulfill their role if not permitted within a context (Sumner, 2010b). Grant and Giddings (2002) explain how the dominance of such ideologies make accusations, such as being ageist and lacking knowledge on OAM, seem natural and truthful, thereby further oppressing practitioners. Consequently, practitioners' efforts are devalued, their power is eroded, and their willingness to pursue this struggle is diminished, all results of oppression as described by Xiao, Kelton, & Paterson (2012). The dialectical reasoning process of CST, exploring what they are told they could do versus the little power they actually have, facilitated an understanding of these burdens carried by the precious few who have this privilege (Fontana, 2004). In this study, this powerlessness was further evidenced by a notion of 'us versus them' which created fear of not wanting to pursue a case legally, a notion that has not been addressed in the Canadian literature. Focus group discussions helped to identify a fundamental contradiction of societal elements: the belief that practitioners have all the legal/professional guidance required to act versus the lack of power they actually experience.

This dominance, referred to as hegemony by Grant & Giddings (2002), have made the interests of this societal structure seem natural and truthful, therefore invalidating practitioners' experiences. Practitioners expressed the urgent need to consider the right of protection from OAM, not reflected in this literature.

Lateral conflict. Conflict amongst practitioners, a characteristic of oppression (Freire, 1972), was evidenced as practitioners expressed conflict either directly to the researcher, or in focus groups when complaints were lodged about other practitioners. It is believed that the lack of ability to resolve cases and the absence of guiding provincial policy clarifying mandate and responsibilities with OAM contributed to this conflict. Although practitioners were compelled to act in these cases, roles in OAM have not been assigned in Ontario. Historically unable to voice their concerns to those with power, practitioners from different disciplines and organizations

instead turned on each other. Participants worked without guiding policies/procedures on OAM. However, organizations cannot be faulted as provincial guidance in Ontario in regard to intervention when OAM occurs within the home is greatly lacking. Eventually, participants voiced that despite good intentions of everyone involved, the current reality, in Ontario, is that OAM is not a mandate of any one organization or profession. Their understanding is supported by the grey legal literature:

> Under the current regime, any person, including health care providers, may report suspected cases of abuse or neglect; however, reporting is not mandated except where the older adult is a resident of a Long-Term Care Home (LTCH) or a tenant in a retirement home" (ACE, 2016, p. 5).

ACE continues by explaining that currently, acting on OAM therefore remains at one's discretion: "The present law in Ontario allows health practitioners to use their discretion when deciding whether to report suspected abuse, enabling the health practitioner, in conjunction with the older adult, to assess the risks and benefits of reporting abuse" (p. 16). Lateral conflict was therefore pointless in resolving the issue as OAM responsibility within the home has not been assigned to any one profession or organization.

Erosion by limited focus on education. In the province of Ontario, the decision was made in 2002, with the creation of the Ontario Network for the Prevention of Elder Abuse (now Elder Abuse Ontario [EAO]), to have a non-legislative response to OAM. A provincial, charitable, non-profit organisation, EAO is mandated to implement The Ontario Strategy to Combat Elder Abuse as developed in 2002 (EAO, 2018). There would not be adult protective legislation and instead, the approach would be one of working together as "fifty-three community response networks" (LCO, 2012, p. 170) providing education for both the public and practitioners with the goal of preventing OAM (Hall, 2009b; Podnieks, 2008). However, study participants described a necessary refocus by networks to goals of prevention and education as a

"community response" was not possible within the current context. A consultation of a list of networks on the provincial website (July 7, 2019) now lists 39 prevention networks, with only four names reflecting a possible OAM 'response' (Elder Abuse Ontario, 2018). The provincial mandate of education has not changed since 2002. Although the EAO works diligently to offer innovative educational opportunities to all regions of Ontario, thus fulfilling their mandate under provincial guidance, participants in this study vehemently objected to continued education. They were very knowledgeable about OAM, able to detect risk factors, list its manifestations, detect its indicators and diagnose its presence and form. During the course of this study, the province was promoting a new education program and some members had assisted hoping to gain new knowledge on intervention; instead, they left insulted and discouraged that perhaps the provincial government focus would never change. This state, that of knowledgeable practitioners who implore the province to progress with intervention, is not new. Cupitt (1997) voiced concerns that providing education in itself was of little benefit if support services for OAM were not available, and expressed the need to advance the field of OAM as has occurred for the field of domestic violence. In keeping with Freire's (1972) notions on oppressive pedagogy, continuing to repeat education on content, without considering the experiential knowledge of participants, is like continually trying to fill a reservoir. Therein lays a fundamental problem with the current provincial educational delivery by experts which does not hear the experiences of practitioners who insist that current efforts are not working in cases of dementia, and within the current provincial context.

Yet, over 20 years have passed since Cupitt's (1997) caution and practitioners continue to be knowledgeable but yet unable to find solutions in the current context. Maintaining the status quo, recipients of such education cannot be empowered. Participants described seeking every possible learning opportunity in OAM. With some subjects, such as consent and capacity, repeated efforts had been made. One participant described having attended consent and capacity

training “at least 20 times, if not more” and jested that perhaps she was simply unable to understand this complex training. However, in focus group discussions, when others shared a similar experience, this practitioner concluded that the training itself was ‘generic’ and failed to address the actual dynamics of OAM and dementia. Halman, Baker, & Ng (2017) explain that for education to be liberating versus oppressive, participants must have the opportunity to share their experiential knowledge and, through dialogue with others sharing similar experiences, be empowered to become agents of change. A CST lens explains that although education is crucial, it does not identify the political and social forces that sustain OAM. If the context of the phenomena is not modified, the same oppression, in this case, the lack of professional agency, will likely continue (Fontana, 2004).

It is time to reconsider the research evidence in the dominant literature which attributes lack of intervention to lack of knowledge, a ‘fact’ which has been repeated for over two decades. Interestingly, an American study identified that education was not predictive of appropriate clinical decisions in OAM; rather, applied knowledge and years of experience predicted recognition and intervention (Meeks-Sjostrom, 2013). Therefore, not considering the experiences of those practitioners nor the contextual influences on them, results in oppression of these practitioners by the dominant literature, prevents understanding of their challenges, and inhibits progression in the field. Participants described their numerous attempts to gain more knowledge but they continued to search in vain for a component of OAM not yet available, that of intervention in their complex cases where factors combined to create a perfect storm: cognitive impairment, caregiver malintent, control behind closed doors of the domestic setting, lack of infrastructure and legislation on OAM in the home, and risk of harm that was not yet imminent and not yet serious enough to be a crime under the *Criminal Code of Canada*. Inquiry about this experience with the practitioners themselves has been long overdue.

It is my position that for the province to continue with this education focus, without creating legislation and infrastructure to support protective intervention for at-risk older adults, is unethical as it is leading to the disillusionment of practitioners who cannot find solutions within an oppressive context. Similarly, but with a focus on the value of detection, Beaulieu & Leclerc (2006) stated that detection of OAM without possible intervention results in discouragement for all involved. Before assigning blame to practitioners who are perceived as not acting in these cases, the oppression of the contexts must be considered as a possible root cause.

Hall (2009b), citing legislation from other provinces, has proposed the development of legislation to go hand-in-hand with Ontario's non-legislative approach: "Perhaps a provincial strategy to combat elder abuse, in connection with potentially effective legislation of this kind (British Columbia), will provide the most productive response, with the strategy raising awareness of the legislative tools and monitoring their effectiveness" (p. 49). In addition, many older adults also want legislative changes. In addressing Ontario's lack of adult protective legislation, Laura Tamblyn Watts, National Director of Policy, Law & Research of the Canadian Association of Retired Persons (CARP) stated: "It's time for government to rethink this system and put supports in place to allow investigation and mandatory responses into elder abuse" (CARP, May 2018). Perhaps more support for such legislation from older adults themselves will encourage the government to reconsider their long-standing non-legislative approach.

Research-practice gap and dominance. The literature is replete with researchers stating that practitioners ought to, should, and must intervene in cases of mistreatment. However, the voices of health practitioners involved in complex cases of mistreatment are seldom heard. According to CST, knowledge is socially and politically constructed by prevailing and powerful ideologies (Fontana, 2004; Ruangjiratain & Kendall, 1998). The interests of powerful societal groups become natural to others and erode their power (Duffy & Scott, 1998; Grant & Giddings, 2002). In Canada, those powerful stakeholders from academia and the legal field have lobbied

for decisions related to intervention that must then be implemented by front-line practitioners. Freire (1972) explained the notion of the elite group, in this case, those with power in OAM, deciding the world of the dominated group, here the front-line practitioners who in turn must comply. As recommended by Norris and colleagues (2013), to transform societal structures and ideologies that constrain action, this study methodology sought to unify research, policy, and practice. However, this thesis, by revealing the distressing experience of practitioners within oppressive legal and academic contexts, specifically urges academics to consider our potentially oppressive power over the experience of these formal practitioners.

As the study progressed, resignation was replaced with empowerment, described by Habermas (1971) as the collective desire for power and action to change one's oppressive reality (Fulton, 1997). The aim of the final phase of this study was the emancipation of practitioners from the dominance of the contexts which impacted their actions in cases of OAM.

Empowerment

Understanding the vulnerability of their experience and the influence of oppressive contexts upon this experience was critical to being empowered to transform this reality (Fontana, 2004; Ruangjiratain & Kendall, 1998). Freire (1972) refers to a similar process of reflection to become aware of the powerlessness, to critique powerful societal structures and dominant ideologies which impact one's powerlessness, and to move towards action. The result, critical consciousness, must entail reflection as well as action. Empowerment however is more effective when considered a collective activity where collaboration by individuals and organizations can lead to community empowerment (Freire, 1972).

Actions. The proposed action projects by participants represented group consensus, thought to positively contribute to their professional agency, to policy and practice, and to care outcomes for mistreated older adults with dementia.

Legislation and infrastructure. The first proposed action was to write a policy brief supporting the need for adult protective legislation and infrastructure and to then forward this brief to provincial policy makers and professional bodies capable of effecting change. This brief would address four components: a summary of their practice realities and inability to protect at-risk older adults mistreated in their homes within the current legal context (Lindenbach, Larocque, Morgan, & Jacklin, in preparation; Lindenbach, Morgan, Larocque, & Jacklin, in preparation); support for Bill 148, the *Protection of Vulnerable Seniors in the Community Act, 2015*, which has not moved beyond the Standing Committee on Social Policy (Legislative Assembly of Ontario, 2015); the vulnerability of dementia as the term is not defined in Bill 148; and the need for supportive infrastructure in the application of such legislation. Interestingly, every focus group overwhelmingly wanted to pursue the policy brief. To maximize the outcomes of this action phase, groups agreed to pursue other projects as long as they could all contribute to the policy brief. Deemed the most important action project that needed to result from this study, it will therefore be a shared project throughout Northeastern Ontario.

It must be clarified that participants were not simply arguing for mandatory reporting without creating infrastructure, more precisely an institution to whom the OAM could be reported and policy and procedures specific to these cases for all organizations and practitioners. This finding echoes the views of researchers in a rural South Ontario region who explained that mandatory reporting without infrastructure and without assigning OAM to any one profession or any one organization would be pointless (MacKay-Barr & Csiernik, 2012). Mixson (2010), an American researcher, offers an interesting analogy for this required combination describing OAM law as the ‘skeleton’ of a program, and the needed infrastructure as the ‘flesh’ that puts the program into effect. She continues by describing the support of infrastructure, all issues that study participants raised: addressing capacity determination, what constitutes sufficient risk and

when to intervene, confidentiality and disclosure of information, the role of protective services versus guardianship, and accountability.

Such infrastructure is strongly lacking in Ontario; in fact, participants described it as non-existent. The importance of this infrastructure, with "clear guidelines on the roles and responsibilities of all actors" has been raised by others in similar legal context without adult protective legislation (Beaulieu et al., 2017). In this study, by drawing parallels between possible protective interventions for children, adults with developmental delay, and victims of intimate partner violence, with those possible interventions for older adults, key OAM obstacles encountered in practice were revealed. This discussion also highlighted the current problematic need to "borrow" inappropriate interventions from other fields for older adults with dementia such as suggesting women's shelters for older adults with dementia, safety planning by giving a victim a list of emergency numbers and having the client prepare a bag of necessities in case of emergency (Ministry for Seniors and Accessibility, 2016). Developing an infrastructure would also require a profound shift in the home care ideology of a system that currently heavily relies on informal caregivers, even when not well-suited or perpetrating the OAM. Instead, the formal system would have to assume care for its older adults when families cannot properly fulfill this duty.

Participants offered numerous positive outcomes of protective legislation and infrastructure specific to older adults: acknowledging older adults' worth, their right to protection, their dignity; addressing the current ageism of lack of protection for older adults; placing adult/senior welfare and protection, just as child welfare and protection, within the responsibility of society; offering intervention possibilities in the home based on suspicion as can be done with child abuse; preventing the POA or SDM from blocking access to the home; providing authority for police officers to enter the home; not requiring a victim statement to proceed with criminal charges; changing the predominant rhetoric on empowering older adults

which is not appropriate with the progression of dementia; addressing current challenges when powerful institutions do not accept practitioners' evaluations of diminished capacity; and, finally, eliminating the current barrier of privacy legislation which requires imminent and serious risk to warrant disclosure of OAM concerns.

Discussion occurred about a current piece of proposed legislation: Bill 148, the *Protection of Vulnerable Seniors in the Community Act, 2015.* This bill would:

> …make it a requirement for regulated health providers to report any reasonable suspicion that a senior is being abused or neglected… to report the suspected abuse to a law enforcement officer, the Public Guardian and Trustee, or another prescribed person… The Public Guardian and Trustee is required to investigate the report …This requirement applies even if the information that is required to be disclosed is confidential or privileged, unless the information is subject to solicitor-client privilege (Legislative Assembly of Ontario, 2015).

Despite supporting this bill as a way forward to effectuate political change, specifically lowering the legal threshold from reasonable grounds to reasonable suspicion, caution was urged against implementing a law without the supportive infrastructure. (The status of this proposed legislation remains unclear; communication with the Ministry for Seniors & Accessibility has not been returned).

Specifically, for their cases of OAM and dementia, participants wanted legislation that would recognize risk, legitimize OAM in the home as domestic violence legislation does for intimate partner violence, and uphold the rights of older adults to protection from mistreatment. These components are reflected in the following recommendations of benchmark Canadian legislation by Hall (2009b):

> Domestic violence legislation that is inclusive of older adults and the kinds of relationships in which they may experience domestic abuse, defined broadly to include non-violent

> forms of abuse including exploitation, is (potentially) an extremely effective approach to elder abuse, in combination with the kinds of education strategy that the government of Ontario has undertaken...Limited adult protection legislation, as provided for by British Columbia's Adult Guardianship Act Part 3, should be accompanied by human rights legislation similar to Quebec's Charte Article 48 to provide protection from exploitation. (p. 48)

The road to legislation in Ontario will be a long one. Comments such as "We must empower seniors and help them to navigate the justice system in order to ensure that their voices are heard in court" (Federal/ Provincial/ Territorial Safety and Security for Seniors Working Group, 2007) reveal an underlying assumption that all older adults have the cognitive ability to be empowered and to be able to understand the judicial system. Many in Ontario who have the power to influence legislation are averse to the attribute of vulnerability to older adults (ACE, 2008; LCO, 2012). As well, different perceptions of vulnerability influence intervention: cases described by practitioners revealed significant risks requiring protection while ACE (2016) states that "vulnerable capable adults should be offered assistive, not protective, services" (p. 14). However, others have explained how autonomous older adults and at-risk older adults require very different approaches; one of empowerment/advocacy as a first option or a protectionist approach when cognitive impairment prevents autonomy (Anetzberger, 2000; Choi & Mayer, 2000). Donovan & Regehr (2010) remind us of our ethical dilemma to balance our duty to protect the safety of the at-risk older adult with their right to confidentiality and autonomy, whichever is the least harmful.

Community empowerment. A second project entailed disseminating this message at the grass-roots level of one's community by those with experiential knowledge in order to positively influence policy makers in matters of OAM and dementia. A reflection on the rhetoric of many documents on OAM revealed a troubling paradox: those who face cases of OAM have the

greatest responsibility but yet hold the least power to effectuate change. As per CST, participants were encouraged to become "social agents…willing to put the research findings into practice" (Comstock, 1982, p. 379). Therefore, the action chosen by this focus group was to present before local council in order to impress upon them the need to address dementia and OAM. As per one participant, this political involvement required that health care and social services practitioners become "political animals" and not be afraid to do so in order to inform community leaders. This action was deemed essential to moving beyond the status quo. Steps to move the project forward would be to understand the current status of the provincial and national dementia strategies, review the literature on Friendly Aging communities and the *Rising Tide* report on the projections of dementia impact (Alzheimer Society of Canada, 2010b); any successful community models on OAM and dementia; prepare the presentation to possibly include the policy brief described above; and present to local council. Also suggested was inviting local leaders to OAM committees to sensitize them to the OAM risks to those living in their homes within their community. If the experience was positive, the same process could be replicated in other Northeastern Ontario communities, especially those rural and northern which were afflicted by human and community resource concerns.

Shared language. The third project aimed to pilot and adopt evidence-based tools on OAM to be adopted by community organisations. Practitioners did utilize evidence-based tools for other issues within their practice but were not aware that OAM tools for screening and identification existed. When adopted by multiple practitioners, these tools could also serve as communication guides between organizations. These objective tools, it was envisioned, could: offer language for credibility as participants were challenged to transform their intuitive thoughts and observations into the objective factual information required by those making decisions (i.e., supervisors, police, lawyers, resources such as OPGT); provide confidence to communicate concerns and therefore be empowering; provide guidance about the information that is required

by different practitioners within the system including police, the OPGT, the HCCB; and provide a process by which different practitioners, for example, unregulated personal support workers within the home, could communicate witnessed risk. Language to be addressed included capacity assessment/evaluation, disclosure of confidential information, level of risk in the home, evidence and suspicion to warrant entry into a home, degree of harm and imminence, not acting in one's best interest, indicators of OAM and current guiding legislation. This is in keeping with Habermas' (1984) notion of communicative reason, whereby front-line practitioners did not feel that they were able to engage with legal institutions on an equal footing as their values of protection of the at-risk collided with the dominant ideology of older adult autonomy. Existing validated paper pocket tools prepared by the National Initiative for the Care of the Elderly (2012) were distributed to participants for an initial review. A literature review for newly developed and validated tools will be conducted and the group will review these findings. Conducting a multi-organization pilot of chosen tools, and education on each other's professional language and guiding legislation, were activities that this group wanted to pursue.

Situation table. A fourth proposed action project was the creation of a situation table for OAM to address professional practice and intervention in their community. Two primary reasons fueled this decision: the importance of support and consultation with these complex cases provided by one's team and the need to address these cases within the social-legal-health care contexts.

In regions where participants were not the sole employee in a satellite office, they described their organizational team as their primary source for support, debriefing, consultation, and guidance. What wasn't explicit, but could be inferred from this study, was that not sharing with others, and thereby remaining isolated with the burden of these cases, could be distressing and not conducive to intervention. Past research with OAM has demonstrated the need for managers and teams as "alliances" in complex OAM cases (Sandmoe & Kirkevold, 2011, p. 94).

Also, although speculation, given that these participants chose to share their cases based on their interest in OAM, it is possible that many more practitioners struggle with these cases but did not come forward. Indeed, the latter may be more perplexed with their cases than study participants. A situation table would therefore offer support to all practitioners regardless of their level of exposure to these cases.

As well, during focus groups, participants shared frustration about not having the answers with specific expertise such as legislation, roles, financial institutions, mental health care, home care, to name but a few. Currently, practice in some communities was to informally reach out to colleagues in other sectors with whom practitioners had positive working relationships from past cases. Some rural and northern practitioners did not have this resource and felt very alone and unsure on how to proceed in cases. A situation table would provide the ability to tap into valuable expertise outside of one's team. Representation with expertise in police matters, legal counsel and town council would also be needed as in all five regions, there was currently no legal and little law enforcement representation on any OAM network which primarily consisted of health care and social services practitioners.

This table would bring together all community stakeholders interested in OAM, similarly to how current OAM Ontario networks currently meet to have generic discussions about community issues for older adults. Then, situations requiring specific attention would result in the creation of a situation table, where a second meeting of those affected services would occur to collectively strategize on how to improve that situation. Situation tables do exist with other at-risk populations, such as mental health, but imminent and serious risk are also criteria for consideration of a case. One participant recommended a multi-sectoral four-filter approach, developed by the Ministry of Community Safety and Correctional Services in consultation with policing partners and the Privacy Commissioner of Ontario. This framework has served as

guidance in sharing personal patient information while abiding by privacy legislation in a multi-sectorial risk intervention model (Government of Ontario, 2018b).

The principle of interprofessional teamwork was appealing to all. Within their own organizations, practitioners described positive outcomes from teamwork for issues other than OAM in various forms: situation tables, weekly huddles, and risk management meetings. However, there were challenges and sustainability was not always possible. In this particular community, an OAM case review team was initiated but did not last. As well, in most participating regions of this study, very few teams served this function. While it is exciting to imagine a positive resource for these practitioners and their community, reflection on failed attempts is essential. Reasons offered for lack of sustainability included: challenges to confidentiality, lack of human resources, inability to resolve cases, and rising caseloads preventing members from consistent participation.

Next, participants in all communities shared the challenge of advancing projects on OAM due to their full-time employment obligations. Having a funded position to strictly coordinate/lead this table was viewed as a driver for success. Such time-limited funding had been obtained in some Southern Ontario communities and a grant proposal would be required if the group wished to proceed. Piloting the four-filter approach to provide a formalized process to collaboration, while respecting privacy legislation, would be attempted.

Once the consultation table was in place, dissemination of its existence would be shared with organizations within the community. A tracking mechanism (while maintaining confidentiality), would be essential to tracking the success and challenges of the initiative. The scope of the project, either being a small community or a larger regional consultation group, was to be considered. Given the isolation of some rural and northern practitioners, where human resources and expertise might be lacking, a regional situation table could possibly provide consultation by teleconferencing.

Supporting the caregiver. The final project sought to recognize the need to address compassionate fatigue in cases of OAM and dementia. Participants described many cases of caregiver exhaustion, and their inability to address this adequately within the confines of the present health and community services context. Current home care service plans, based on patient assistance needs for activities of daily living, did not sufficiently address caregiver needs. Participants wanted to address this gap. Although this risk factor has been refuted by past OAM literature (Gainey & Payne, 2006), other studies have confirmed its contribution to OAM when dementia is present (Alzheimer Society of Canada, 2010a; Cooper, Selwood, Blanchard, & Livingston, 2010; Kalapatapu & Neugroschl, 2009). Furthermore, CIHI (2010b) reported that rates of caregiver distress rose from 16% when providing care to an older adult without cognitive impairment, to 37% when caring for an older adult with moderate to severe cognition problems, and 52% when caring for an older adult displaying aggressive behaviours. Many ideas were shared so as to prevent duplication of current efforts. Foremost, this support was not to perpetuate the current downloading of responsibilities of care for the older adult with dementia onto the caregiver.

More discussion would be required to achieve conceptual clarity for this particular project. Caregiver respite, although gravely insufficient, was currently provided by two organizations in the form of in-home hours, day programs, support groups, and short-term placement in long-term care. Therefore, if applying for funding, the challenge would be to determine a niche to prevent overlap of existing services. Participants suggested many ideas: proposing a pilot project for a caregiver support program with the goals of preventing mistreatment and crisis; additional in-home respite; compassionate fatigue classes; education on risk of OAM; providing care for caregivers (art therapy, activities); including extended family support (for example grandchildren); partnering with Alzheimer Society on existing caregiver support modules; researching the literature to learn how other countries support their informal

caregivers; performing a scan of services currently offered in Northeastern Ontario where some communities did not have day programs nor respite; focusing on risk factors of isolation and compassion fatigue; preparing a background paper demonstrating why caregiver support is essential to prevent mistreatment; and, once clarity of the project was achieved, assisting the group to prepare a grant proposal to fund a pilot project.

Can Ontario progress? The wide gaps seperating Ontario researchers, policy makers, and practitioners must be addressed so that the field of OAM, and consequently the care outcomes for mistreated older adults in this province, are improved. There appears to be some receptiveness to recognizing the "heightened risk" of older adults with dementia in certain living environments within some Ontario legal literature (LCO, 2012, p. 58). However, instead of acknowledging their potential power to address these risks with legal reform, this same literature continues to propose society's failure to address these risks and the possibility of risk reduction by governmental programs and initiatives. Although the LCO (2012), based on their public consultations with older Ontarians, have recognized the "importance of security" (p. 95), and the growing complexities of elder law with an aging population and rising dementia prevalence, the notions of vulnerability and the need for protection continue to be discouraged (ACE, 2008).

Five Canadian jurisdictions (British Columbia, New Brunswick, Nova Scotia, Prince Edward Island, and Newfoundland and Labrador, Yukon) now have adult protection laws, each varying in scope (CCEL, 2011b; Spencer & Soden, 2007). While the LCO (2012) acknowledges that such legislation creates infrastructure required to address OAM cases, permits access to these older adults and that "mandatory reporting and intervention may be necessary" where "older adults may genuinely be unable to act to protect themselves" (p. 106), the proposed remedy continues to be "greater training and education" (p. 105).

International safeguarding of adults at risk. For progress to occur in this province, I believe that international promising approaches must be considered as therein may lie the path to

address the current impasse between researchers, policy makers, and practitioners. Important changes in ideologies and conceptualizations of OAM are occurring in the United Kingdom, the current leaders in 'adult safeguarding'. These include the consideration of all 'adults at-risk' over the age of 16 or 18 in legislation, versus restricting statutes to 'older adults' (Spencer-Lane, 2010); considering 'risk' versus 'vulnerability' (Stevens, Martineau, Manthorpe, & Norrie, 2017); addressing threshold of harm to facilitate prevention (Williams, 2017); and 'safeguarding' versus 'protection' (Stevens et al., 2017). Such progress is promising as components of different statutes bring possible solutions to the numerous challenges shared by participants in this study. For example, powers of entry in the face of hindrance, duties to make enquiries and specialist safeguarding teams (Mackay & Notman, 2017; Stevens et al., 2017; Williams, 2017) can permit access to and intervention with older adults with dementia isolated by their caregiver while providing support for front-line practitioners. It is hoped that, in Ontario, those with power to effectuate change, are willing to consider a new narrative.

Limitations

This study captured the experiences of practitioners who were willing to share their beliefs, values, and actions with a past case of OAM and dementia within the home context. Given the sensitive and precarious nature of OAM cases, their hidden nature within the home, the lack of organizational and provincial guidance on intervention, and the oppression resulting from legal complexity, it is possible that practitioners with particularly challenging cases did not want to participate and share their experiences. They may have also feared being judged in the open forum of a focus group or concerned of revelation of any incorrect interventions to their employers. Given one organization's concern that study participation would lead to the exposure and critique of internal policies on OAM, it is fair to question if non-participants shared similar fears.

In this study, demographic characteristics of participants such as gender or ethnicity were not collected. This could have provided additional insights, especially given the strong francophone and Indigenous populations in Northeastern Ontario.

I strove to remain cognizant of my preunderstandings with OAM and dementia throughout data collection and analysis. This was achieved by constant self-reflection on thoughts, emotions, and assumptions by journaling, memoing, and returning to drawn conceptual maps of the differences between participants' experiences and my past practice as a community case manager with challenging OAM cases. Although this is a potential bias, it did result in: enhanced critical thinking, knowing when to ask for further details so as not to remain at the surface level of experience; knowledge of past socio-political and health care contexts, without which participant details about current contexts could not have been probed; and an open acceptance of practitioner experiences of doubt, regret and worry, thereby encouraging participants to share their experiences.

Recruitment and retention of participants was challenging, especially in rural and northern regions, due to human resource challenges. In one particular region, this led to decreased participation in both interviews and inquiry focus groups. As a result, insufficient numbers rendered a Phase II action focus group impossible in that region. An offer to join another region's action focus group through teleconferencing was declined as the planned action would not be focused within their own community. Next, long-standing conflict with one particular organization shared by some during interviews and evidenced in some focus group discussions, possibly resulted in the decision of the majority of those participants to not proceed with Phase II focus groups during which participation entailed contributing to a collaborative action project. Lastly, workload obligations and urgent caseload issues prevented some from attending focus groups despite confirmation of intent to participate. Although this led to smaller

groups, the richness of shared experiences and valuable insights resulted in fruitful discussions, which may have not been possible if the groups were too large.

Not all leads resulting from snowball sampling could be followed given the limited time frame of this funded study and the structured two-phase design. Respecting time frames meant that all of Phase I data collection had to be completed in order to prepare the Interim report and proceed to Phase II recruitment. These potential participants, all physicians, were highly respected for their involvement in challenging OAM cases in their communities and may have contributed additional valuable insights into their contextual realities.

Finally, again due to the narrow window of the funded study, action plans for regional projects could only be initiated and ongoing support could not be provided. However, participants understood that the researcher will continue to assist each region with their project, and with time, all would be completed.

Significance

To my knowledge, this is the first study in Ontario that sought to understand the professional experience with OAM in the home. As with the handful of studies conducted with home care practitioners in similar socio-political contexts, practitioners described fear for the older adult and controlled access to the home by the mistreating caregiver. These study participants described this experience, behind the closed doors of the home, as a destabilizing storm which they had to weather in order to come to the discomforting realization that the older adult with dementia was indeed being mistreated by their family member.

In addition, this study is the only located study to consider the notion of professional agency, that of having control over a situation and of perceiving interventions as meaningful, with OAM and dementia. Practitioners experienced a lack of professional agency. Witnesses to abuses of power and having to tolerate risk within the home, they felt powerless to change the outcomes for the older adult. This study focused on how societal ideologies and structures

influenced professional agency and discovered current contexts to be oppressive to practitioners. In some cases, when their efforts were futile and they failed to end the OAM, practitioners actually considered themselves, as representatives of the structures of health, social service, and law enforcement, to be part of the societal problem. Also, within the home, the overreliance of a health care system on the family caregiver and societal assumptions of good-will family caregiving, were troublesome for practitioners who witnessed otherwise. Next, a focus on rural and northern regions revealed an isolation of both the older adult/caregiver dyad and the practitioner who functioned with limited human resources and community services, covered large sometimes unrealistic geographical regions, and assumed a wider scope of practice to meet basic needs of mistreated older adults such as food, heat, and shelter. Lastly, the focus on the legal context, complex, prioritizing a family ideology, not recognizing risks within the home, and all too frequently unsupportive, has not been addressed in the scientific literature.

Traditional assumptions of power of health, social service, and law enforcement practitioners were questioned in this study. Without authority in the home, ceasing mistreatment by a malintent caregiver was challenged. Contextual factors constrained action in the home rendering practitioners, regardless of societal beliefs and information provided in resource materials, powerless and in a perpetual provincial cycle of non-resolution. Lateral conflict resulted from these incorrect assumptions of power and complex legislative context. Stagnation and losses in the field disenfranchised practitioners, possibly contributing to the erosion of OAM networks within this region.

The CST lens of this study facilitated a depth of understanding of this multifaceted experience embedded within contextual influences. The rich data from the practitioners and the resemblance of their unsuccessful struggles to bring about positive outcomes for these older adults with dementia cannot be ignored. The heterogeneity of the sample, the wide years of experience of the participants, the inclusion of rural, northern, and urban regions, and the

richness of the data obtained, support the transferability of these findings within the province of Ontario. They might also be transferable to other regions that share similar home health, and socio-legal contexts; these contexts have been sufficiently described in a prior paper (Lindenbach et al., in preparation) to allow the reader to determine transferability of findings to their own region (Koch, 2006).

In this study, practitioners demonstrated a personal commitment to mistreated older adults within contexts that constrain action, fail to provide guidance, and create a personal/ professional /legal ambiguity for practitioners who want to act. Donovan & Regehr (2010) have addressed challenges resulting from this ambiguity within the Canadian OAM field but concluded that practitioners must simply "resolve their personal struggles" with OAM cases (p. 180). The cases shared by participants in this study described at-risk older adults with advancing dementia whose care was completely controlled by the mistreating caregiver within the home. Despite these challenges, practitioners persevered, sometimes playing a role in order to maintain services in the home, always maintaining a professional armour so as not to trigger further mistreatment, and fully convinced of their duty to advocate for the mistreated older adult who could no longer do so for themselves. By continuing to disregard these struggles, the gap between research and practice will simply widen as knowledge and policy development are hampered.

Lastly, although Beaulieu and colleagues (2017) have recently conducted an action research project in Montréal, Quebec on OAM, this study is a first to propose the empowerment of practitioners with cases of OAM and dementia. To the best of my knowledge, these are the only two action studies to be undertaken with practitioners who encounter OAM. Underpinned by CST, the two-phase design facilitated a process of understanding, critique, and empowerment. Empowered, practitioners proposed action projects to improve policy, community response, and

practice. These actions offer the potential for the development of a critical mass of practitioners empowered to challenge the status quo with OAM in this province.

Recommendations

Practitioners perceived a professional duty to protect the older adult from the harm of mistreatment. Within the current home health care, geographical, and socio-political contexts, they cannot and are forced to legitimize their concerns to those outside the home. Recommendations are now offered to address the research-policy-practice gaps in this province.

Research

1) This research revealed several findings not previously reported in the literature that will require additional scientific studies to corroborate and gain deeper insights. Presented under the three key themes, these include:

   Experience: the emotions and moral knowledge which serve as a catalyst propelling practitioners to persevere with their OAM cases, the stoic professional armour doned to protect the older adult and one's professional image, their feelings of abandonment when managing cases without adequate systemic support, the guilt of waiting for and wanting the crisis that would effectively bring the OAM outside of the hidden home context where they were powerless to stop it, and the doubt and regret that remained with them from past cases.

   Contextual influences: the burden of maintaining the OAM secret until disclosure was permitted under legislation, the moral distress of being unable to fulfill their socialized professional role, the incorrect assumption that family, friends and neighbours in rural regions will compensate for formal service limitations in cases of OAM, as well as the false belief of police and physician power in these cases, the lateral conflict resulting from oppression, the historical stagnation, systemic pressures and losses pertinent to OAM in

this province, the challenges with the capacity evaluations/assessments process, and the notions of thresholds of evidence when OAM occurs in the home.

Need for empowerment: a perpetual cycle of non resolution and self-driven efforts related to the lack of ownership of OAM occurring in the home in this province, the problematic assumption of practitioner lack of knowledge, the bending/breaking of rules occurring when unable to resolve the OAM, the unrealistic knowledge demands on practitioners to be competent with numerous pieces of legislation, practitioners' perception of lack of adult protective legislation as a form of systemic ageism, and the importance of validating practitioners' experiences.

2) Further research on contextual influences with practitioners who encounter OAM and dementia within the home context, in Canadian provinces with adult protective legislation and infrastructure and in those provinces without legislation. Studies could compare OAM case outcomes within both legal contexts. Similarly, studies with urban, rural, and northern practitioners could identify any inequities in community services required by these dyads and human resources, and again, the impact on case outcomes. Lastly, collaborative national and international research comparing experiences in Ontario with practitioners from areas supported by adult protective legislation on specific challenges such as access to the home.
3) Further studies are required on the experience of practitioners with OAM and dementia of different cultures and in all contexts. Too many studies have focused on their knowledge, or on the act of reporting, while too few have attempted to understand their experience. An understanding of cultural diversity may also provide additional insights into this experience.
4) Further research is required with various practitioners including law enforcement,

lawyers, and physicians who have had past cases of OAM and dementia to clarify societal assumptions of their positional power.

5) Case studies focusing on intervention to identify what strategies, pieces of legislation, societal infrastructure were successful and which were not.

Policy

6) For too long in Ontario, the focus has been on education. This repeated focus, since 2002, is not achieving the desired outcome of prevention and is instead resulting in disenfranchising those practitioners who are questioning if the province is ever going to advance. Current Ontario laws fail to recognize the controlled and hidden home context and the problematic family ideology of legislation. Ontario is urged to move towards a legislative approach for the home context, as has been done for long-term care and residential care. As well, an accompanying infrastructure is required to assign responsibility of OAM to one or more professions or organizations. The infrastructure would serve to support the implementation of the legislation. This, in turn, would permit organizations to develop their policies/procedures on OAM and assign appropriate human resources versus the current self-driven efforts of a precious few. Legislation and infrastructure would serve to clarify the current personal/professional/legal ambiguity impacting practitioners. Legislation would also raise OAM to the proper level of societal concern just as child and domestic abuse that are no longer acceptable. Promising legal and policy reform approaches in the United Kingdom and British Columbia should be considered.
7) The consideration of ‘at-risk’ and ‘all adults’ versus older adults should guide the elaboration of a new definition of mistreatment to recognize that older adults do not make a homogenous group; some are highly autonomous while characteristics other than age

increase risk warranting protection from OAM. Protection from OAM should also be considered a basic human right and not an affront to one's autonomy.

8) Current privacy legislation which prevents disclosure of concerns until significant risk of serious bodily harm, violence, suicide, or imminent danger (CCEL, 2011b) places the burden of maintaining the secret of OAM on the practitioner until this point is reached and prevents legal intervention until a crisis occurs. Although surely not intended by this law, within the hidden home context, such is the outcome. Such changes have been legislated in the United Kingdom.
9) Current legislation surrounding capacity assessments presents barriers to intervention when institutions do not consider the practitioner's capacity evaluation and the family will not assume the cost of a capacity assessment by a formal Capacity assessor. As some regulated health professionals such as nurses can complete the extensive training to become capacity assessors in Ontario, provincial bodies should encourage nurses to do so, thus increasing its availability and ensuring that concerns by those who can most readily access the dyad are heard. The LCO, ACE, and OPGT are asked to clarify if a health practitioner's evaluation of capacity can be considered as evidence in requests for assistance.
10) The home care system must recognize the needs of family caregivers and provide increase service allotments to recognize the potential for OAM with increased caregiver stress when caring for an older adult with dementia. In provincial health documents, the dominant ideology of right to live at-risk and considerations of unacceptable risk should be reconsidered as these influence decision-making and possibly result in the disregard of OAM cases.
11) In rural and northern regions, provincial provisions must be made to ensure services that are essential to supporting an older adult/caregiver dyad such as day programs, in-home

respite, and long-term care respite beds. Also, human resources of pertinent services (home care, social services, police), must be ensured to prevent inequities.

Practice

12) Academics and researchers, considered experts in their field, must recognize their ability to influence the narrative, and its potential to disempower front-line practitioners. In the creation of resources for practitioners, that dominant ideology can infect discourse as has occurred in this province. Accusations of ageism and of self-protection are repeatedly leveled against practitioners in the grey literature and their primary source, easily traced as it is dominant, is certainly academia.
13) When preparing resources for practitioners, whether at one's organizational level or by professional bodies, care must be taken with recommended interventions. For example, it is not acceptable to direct practitioners to call police anonymously, nor, in cases of progressing dementia is it advisable to have the person prepare a suitcase or provide them with a list of emergency numbers.
14) For any education endeavor, practitioners should be asked what it is they require. The need for repetitive training on capacity and consent in this province is an indicator that it is probably not addressing the complexities of OAM and dementia. For example, practitioners may ask for education on the *Criminal Code of Canada*, how and who to contact at the OPGT, and what information is required by police for them to lawfully enter a home. They are knowledgeable in matters of signs, risk factors, indicators, forms and diagnosis of OAM and do not need further training.
15) Practitioners must be encouraged to be vocal with professional bodies, community leaders, and their member of parliament. As stated by one participant: "we need to become political animals, we can't be afraid to do that… unless you have community leaders informed and prepared to take action, we we're still going to be sitting at

committees ten years from now having the same conversation". To achieve this objective, action studies that engage practitioners in research that is valuable to practice is encouraged.

16) Students in health care, social work, and police programs should receive mandatory education on OAM prior to their entry to practice. Education of the public should also be maintained to sensitize society to the negative impact of ageism on OAM.

Conclusion

Within the home context, practitioners experienced a lack of professional agency with their cases of OAM and dementia. The hidden home context and strong family caregiving ideology have contributed to maintaining the family, and consequently, the practitioners who have access to them, responsible for OAM. In northern and rural areas, practitioners faced additional challenges resulting in isolation of the older adult/caregiver dyad as well as the practitioner. As OAM does not rest on its own legislation and infrastructure in this province, health and social service practitioners were expected to have knowledge of numerous pieces of applicable legislation, complex legal knowledge that fell outside their scope of practice. Although unrealistic, it is currently expected that practitioners obtain this knowledge, and be correct in its application. Within these oppressive contexts, practioners' professional agency was greatly reduced.

A critical methodology was instrumental in: enabling participants to explore past cases, some that they had not necessarily previously identified as mistreatment, facilitating critique of socially dominant ideologies and structures, encouraging self-reflection on beliefs, values, and assumptions and dialoguing about contextual challenges to practice with OAM and dementia. The study exposed the unachievable ideal of professional agency in these cases, and subsequently facilitated the empowerment of practitioners to collaboratively develop action

projects to improve policy, practice, and care outcomes for mistreated older adults in their communities.

In discussing empowerment, Chavasse (1992) states that practitioners "cannot empower others...until they are empowered themselves" (p. 532). This speaks to the most important consequence of lack of agency in practitioners. When powerless, practitioners may become disenfranchised and cease considering action in OAM cases as their duty (Fulton, 1997). An understanding of professional agency and a critique of contextual factors became a catalyst propelling practitioners to act towards changes in policy, research, and practice. By permitting practice to inform research, the field of OAM and dementia might gain much needed knowledge to change the status quo.

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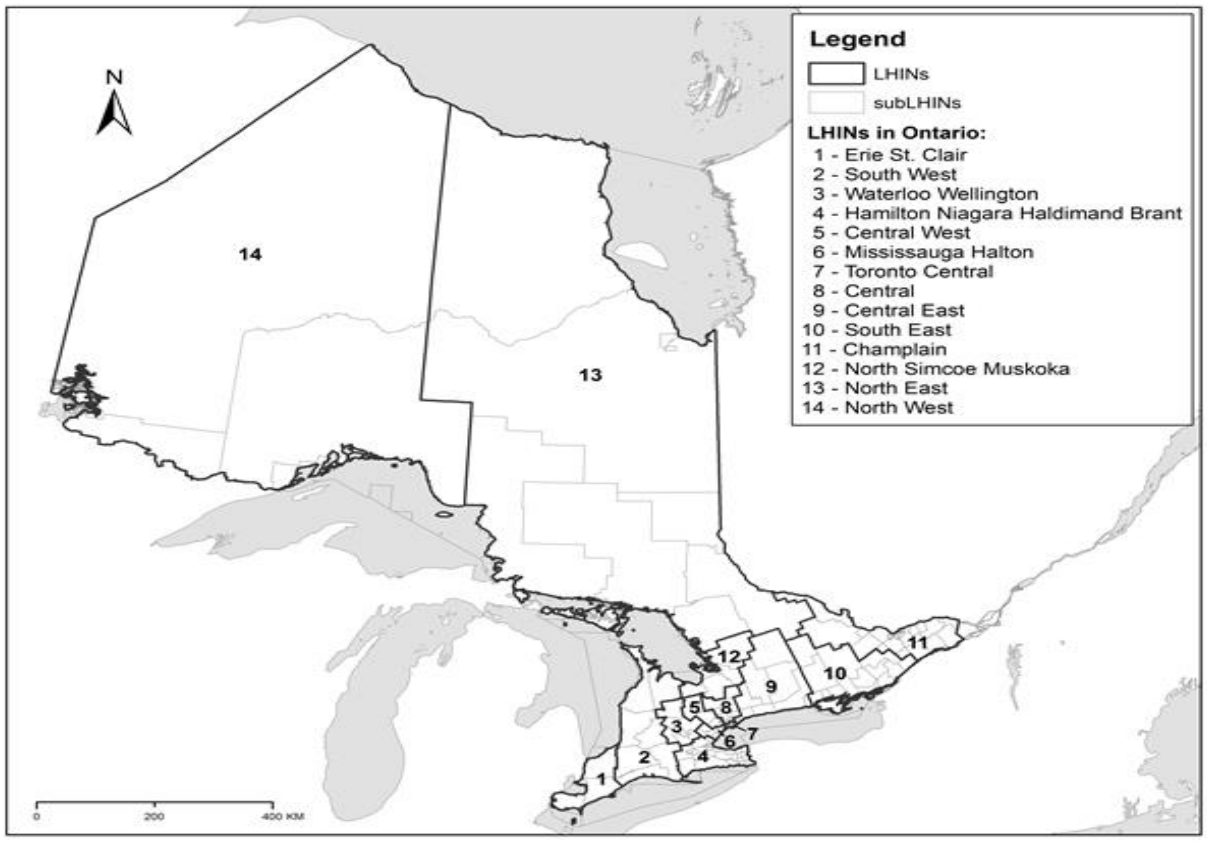
Appendix A- Map of Northeastern Ontario (Zone 13)



Source: Statistics Canada (2015)

Appendix B-Organizational Information Letter

Study Title: OAM, dementia, and the family caregiver in the rural Northeastern Ontario home: The influence of context on professional agency

Institution: Laurentian University, School of Rural and Northern Health

Principal Investigator: Jeannette Lindenbach, RN, MSc.N, Ph.D. candidate

Co-Investigators: Kristen Jacklin, Ph.D. Northern Ontario School of Medicine (Supervisor)
Sylvie Larocque, Ph.D. Laurentian University (Committee Member)
Debra Morgan, PhD. University of Saskatchewan (Committee Member)

Dear Sir, Madam,

I am writing to request the participation of your organization in a research project. I am a Ph.D. candidate and the principal investigator conducting a research study through Laurentian University School of Rural and Northern Health, in Sudbury, Ontario, Canada. This letter explains the purpose of my study, potential risks and benefits, and participation of your employees. Contact information is provided to answer any further questions or concerns you may have related to this project.

Purpose and description of research

In Ontario, there is no formal structure to guide practitioners in cases of OAM, which often leaves them unsure of their role. This research project aims to discover the challenges to practitioners as they encounter and contemplate these types of cases. How they feel about their ability to react and act in these cases are valuable experiences to share. Additionally, I am interested to learn about any differences in practitioners' ability to act in the urban or rural context. Lastly, this study is designed to ensure that the findings contribute to professional empowerment and to improving their practice with these cases.

Participation

I am inviting practitioners who have had a past case of older adult with dementia mistreated in the home to participate in this study. Five primary organizations are being invited to participate in this research. Participation will consist of interviews, reflecting on some questions in a journal, and/or joining focus group discussions. Practitioners will be invited to participate at different phases and in specific methods based on their current role in these cases and their desire to work towards collaborative change.

• Phase I will consist of interviews with individual participants. An interview will be arranged at a date, time and location convenient to your employee. They will be asked to share their experience with a past case of older adult with dementia mistreated by a family caregiver. I will then ask them to reflect on some follow-up questions in a journal in the format of their choice (electronic or paper format) and return the journal electronically or via prepaid mail within 1 month of receipt.

•Focus groups will be organized to discuss challenges and opportunities in cases of OAM and dementia. Travel costs to a central location, at a rate of 55¢/km, will be reimbursed and a light lunch provided.

•After a preliminary analysis, I will share group findings with all participants of Phase I with the aim of sensitizing practitioners to each other's challenges and opportunities within their roles and regions. All findings will be interpreted at the group level, fictitious names will be assigned, and composite stories will be developed for cases reported.

•Phase II will be an empowerment phase where I will invite all participants wishing to collaborate towards change to come together in their specific geographical area. Travel costs, at a rate of 55¢/km, will be reimbursed and a meal will be provided.

Participants' rights

Participation in this research project is voluntary. Participants will have the right to decline to participate. They may change their mind at any time and withdraw. They may choose not to answer questions or to stop participating at any time. Whether they choose to participate or not will not be disclosed to the employer or supervisor.

Potential harms, risks, or discomforts

Organizations have offered their meeting rooms to conduct interviews and focus groups. Funds have also been obtained to rent a meeting room as needed. All participants will be offered both alternatives and preferences will be respected.

Although as a professional, they may encounter such cases in their everyday work life, sharing of the challenges in this practice might elicit distress. I will conclude each interview by offering them the contact information of the employee assistance program of your organization.

At the onset and conclusion of focus group sessions, participants will be reminded of the importance of maintaining confidentiality. All interviews and focus group discussions will be audiotaped and transcribed for accuracy. A regional consultant will co-facilitate focus groups. As questions may arise in the focus group setting, she will offer community resources that practitioners may pursue for their cases.

Prior to data collection, the legal considerations of sharing information regarding OAM will be explained. In Ontario, there is no legal responsibility to report OAM as there is no adult protective legislation. However, participants will be informed of existing pertinent legislation (Appendix P) if an older adult or caregiver is at significant risk of serious bodily harm … violence, suicide, imminent danger (Canadian Centre for Elder Law, 2011).

Potential Benefits:

The sharing of these experiences during the interviews and focus groups may have a therapeutic effect for practitioners. Understanding the experience of practice with OAM and dementia will identify factors influencing their ability to reflect and act in these cases. Discovering the challenges to practitioners as they encounter and contemplate these types of cases as well as how they feel about their ability to react and act in these cases are valuable

experiences to share. This knowledge may contribute to increased education, improved agency, the development of guiding policy and procedures, better practice and the creation of interdisciplinary consultation teams. As well, knowledge from this study will inform policy makers, regulatory professional bodies and community organizations about the challenges encountered by practitioners as well as collaborative opportunities. By permitting practice to inform research, the field of OAM can gain knowledge.

Confidentiality

All interview data and demographic information collected will be assigned a code number. Participant names and that of the organization will not appear on any information collected except on the research consent form. The shared information will be summarized along with information obtained from other participants.

Confidentiality nor anonymity cannot be assured in focus group settings. However, participants will be encouraged to not share content of the focus groups.

When the results of this study are published or presented at a research conference, names and any identifying information will not be used. All individual information will be kept confidential and will not be accessible to persons not connected with the research study.

Transcripts and audio recording will be password protected and stored in a locked filing cabinet in the researcher's locked office, located in the School of Nursing, Laurentian University. Consents will be stored separately using the same precautions. All audio data will be destroyed by recycling once findings are published. All paper records will be shredded then cross shredded after completion of the study.

Ethical considerations

As an acknowledgment, participants will receive a USB key with resources pertaining to OAM and dementia and outcomes of the action phase of the study. Hard copy interim and final reports will also be produced and disseminated to participants to share with their organization.

This research proposal has received approval by the Research Ethics Office at Laurentian University. If you would like any additional explanation or have any concerns about this study you may contact a Research Ethics Officer at the Laurentian University Research Office, telephone: 705-675-1151 ext 3681 or toll free at 1-800-461-4030 or email at ethics@laurentian.ca

If you require further information regarding my research project, I would certainly welcome further discussion and can be reached at 705-675-1151 or toll free at 1-800-461-4030, extension 3824 or at jm_lindenbach@laurentian.ca. You may also reach my thesis supervisor, Dr. Kristen Jacklin, at 705-662-7277 or toll free at 1-800-461-8777, or at kjacklin@nosm.ca Please accept my gratitude for your contribution to my PhD research project, to community care, and to the field of OAM and dementia.

Warm regards,

Jeannette Lindenbach

Appendix C- Information Letter for Participants

Study Title: OAM, dementia, and the family caregiver in the rural Northeastern Ontario home: The influence of context on professional agency

Institution: Laurentian University, School of Rural and Northern Health

Principal Investigator: Jeannette Lindenbach, RN, MSc.N, Ph.D. candidate

Co-Investigators: Kristen Jacklin, Ph.D. Northern Ontario School of Medicine (Supervisor)
Sylvie Larocque, Ph.D. Laurentian University (Committee Member)
Debra Morgan, PhD. University of Saskatchewan (Committee Member)

Dear Participant,
My name is Jeannette Lindenbach and I am a Ph.D. candidate and the principal investigator conducting a research study through Laurentian University School of Rural and Northern Health, in Sudbury, Ontario, Canada. This letter explains the purpose of my study, potential risks and benefits, your participation, and your rights as a participant. Contact information is provided to answer any further questions or concerns you may have related to this project.

Purpose and description of research
In Ontario, there is no formal structure to guide practitioners such as yourself in cases of OAM, which often leaves them unsure of their role. This research project aims to discover the challenges you encounter with these types of cases. How you feel about your ability to react and act in these cases are valuable experiences to share. Additionally, I am interested to learn about any differences in practitioners' ability to act in the urban or rural context. Lastly, this study is designed to ensure that the findings contribute to your professional empowerment and to improving your practice with these cases.

Participation
I am inviting practitioners who have had a past case of older adult with dementia mistreated in the home to participate in this study. Five primary organizations are being invited to participate in this research. Participation will consist of interviews, reflecting on some questions in a journal, and/or joining focus group discussions. Some organizations have offered their meeting rooms to conduct interviews and focus groups. Funds have also been obtained to rent a meeting room as needed. All participants will be offered both alternatives and preferences will be respected.
You will be invited to participate at different phases and in specific methods based on your current role in these cases and your desire to work towards collaborative change.

- In Phase I, an interview will be arranged at a date, time and location convenient to your employee. They will be asked to share their experience with a past case of older adult with dementia mistreated by a family caregiver. I will then ask them to reflect on some

follow-up questions in a journal in the format of their choice (electronic or paper format) and return the journal electronically or via prepaid mail within 1 month of receipt.

- Focus groups will discuss challenges and opportunities in cases of OAM and dementia. Travel costs to a central location, at a rate of 55¢/km, will be reimbursed and a light lunch provided.
- After a preliminary analysis, I will share group findings with participants of Phase I with the aim of sensitizing practitioners to each other's challenges and opportunities within their roles and regions. Findings will be interpreted at the group level, fictitious names assigned, and composite stories developed for cases reported.
- Phase II will be an empowerment phase where I will invite all participants wishing to collaborate towards change to come together in your specific geographical area. Travel costs, at a rate of 55¢/km, will be reimbursed and lunch provided.

Participants' rights

Participation in this research project is voluntary. You have the right to decline to participate. You may change your mind at any time and withdraw. You may choose not to answer questions or to stop participating at any time. Whether you choose to participate or not be disclosed to your employer or supervisor.

Potential harms, risks, or discomforts

Although as a professional, you may encounter such cases in your everyday work life, sharing of the challenges in this practice might elicit distress. I will conclude each interview by reviewing contact information of the employee assistance program of your organization. All interviews and focus group discussions will be audiotaped and transcribed for accuracy. The regional consultant will co-facilitate focus groups, and, as questions may arise, she will offer community resources that you may pursue for your cases.

Prior to any data collection, the legal considerations of sharing information regarding OAM will be explained. In Ontario, there is no legal responsibility to report OAM as there is no adult protective legislation. However, participants will be informed of existing pertinent legislation an older adult or caregiver is at significant risk of serious bodily harm … violence, suicide, imminent danger (Canadian Centre for Elder Law, 2011).

Potential Benefits:

The sharing of these experiences during the interviews and focus groups may have a therapeutic effect for you. Understanding the experience of practice with OAM and dementia will identify factors influencing your ability to reflect and act in these cases. Discovering your challenges as you encounter and contemplate these types of cases as well as how you feel about your ability to react and act in these cases are valuable experiences to share. This knowledge may contribute to the development of guiding policy and procedures, better practice and the creation of interdisciplinary consultation teams. As well, knowledge from this study will inform policy makers, regulatory professional bodies and community organizations about the challenges you face as well as collaborative opportunities. By permitting practice to inform research, the field of OAM can gain much needed knowledge.

Confidentiality:

Interview data and demographic information collected will be assigned a code number. Your name and name of your organization will not appear on any information collected except on the research consent form. All shared information will be summarized with that of other participants. Whether you choose to participate or not will not be disclosed to your employer.

Confidentiality nor anonymity cannot be assured in focus group settings. However, participants will be encouraged not to share content of the focus groups.

When the results of this study are published or presented at a research conference, your name and any identifying information will not be used. All individual information will be kept confidential and will not be accessible to persons not connected with the research study. Transcripts and audio recording will be password protected and stored in a locked filing cabinet in the researcher's locked office, located in the School of Nursing, Laurentian University. Consents will be stored separately using the same precautions. All audio data will be destroyed by recycling once findings are published. All paper records will be shredded then cross shredded after completion of the study.

Ethical Considerations

As an acknowledgment, you will receive a USB key with resources pertaining to OAM and dementia and outcomes of the action phase of the study. Hard copy interim and final reports will also be produced and disseminated to all participants to share with your organization.

This study has been reviewed by, and has received ethics approval from the Research Ethics Office at Laurentian University. Individual institutional ethical approval has been obtained from your organization. If you would like any additional explanation or have any concerns about this study you may contact a Research Ethics Officer at the Laurentian University Research Office, telephone: 705-675-1151 ext 3681 or toll free at 1-800-461-4030 or email at **ethics@laurentian.ca**. You may also reach my thesis supervisor, Dr. Kristen Jacklin, at 705-662-7277 or toll free at 1-800-461-8777, or at kjacklin@nosm.ca

(**For NE SGC information letter add**: Your Rights as a Research Subject: If you have any questions regarding your rights as a research participant, you may contact the Health Sciences North Research Ethics Board at 705-523-7100, ext. 2409 or by email: reb@hsnsudbury.ca. The Research Ethics Board is a group of people who oversee the ethical conduct of research studies. These people are not part of the study team. Everything that you discuss will be kept confidential.)

Contact information to participate in study

If you wish to participate in the study, please contact me at jm_lindenbach@laurentian.ca or 705-675-1151, or toll free at 1-800-461-4030 extension 3824. It will be my pleasure to meet with you at a time and place convenient to you.

Kind regards,

Jeannette Lindenbach

Appendix D –Text for email recruitment-Phase I

Hello. My name is Jeannette Lindenbach. I am a nurse, a previous case manager with CCAC, and now a nursing professor and PhD student at Laurentian University.

I wanted to put a face to the study in which I am inviting you to participate. This study is based on my interest in learning more about how practitioners in Ontario, such as you, manage cases where older adults with dementia are mistreated in their home. In a larger sense, I want to learn about the forces that come into play influencing your everyday management of these cases. I am interested in the challenges you face when reflecting on your course of action in these cases, deciding upon your interventions, and acting in a way that is meaningful to you. Lastly, I've designed the study to include an action phase where you will be able to network with others in your region towards collaborative change.

The letter attached to this email describes in detail the study design, the benefits and risks of participation, and provides contact information.

Your voice, that of practitioners involved in the day-to-day management of these cases, is absent from the literature. I hope we can change that and, through this study, contribute to your empowerment in these cases.

My contact information is indicated at the end of the attached letter. I hope you will contact me to share your valuable experiences.

Appendix E- Demographic Information

1. Gender Female _____ Male _____
2. Age under 25 years ____ 45-54 years ____
   25-34 years ____ 55 or more years ____
   35-44 years ____

3. Education : Degree _____
   Did you receive any training in OAM? Yes_____ No_____
   If yes, please specify:
   In undergraduate program_____ Agency inservice_____
   Conference or other forums_____
Other_____

Did you receive any training in dementia? Yes_____ No_____
   If yes, please specify:
   In undergraduate program_____ Agency inservice_____
   Conference or other forums_____
Other_____

4. Employment History
a) Year in which you started working with older adults: _____
b) Community or location where you worked the majority of your career:
   _____
c) Do you work on a specific team within your organization?
   _____
d) What is your job title?
   Counsellor _____ Nurse care coordinator _____
   Social worker_____ Supervisor _____
Other (please specify)_____

11. Geographic location of your organization:
   Sudbury_____ North Bay_____
Timmins_____ Kirkland Lake_____

12. In your work, in which area do you primarily work?
Urban_____ Rural _____ Both _____
13. If you wish to receive data analysis from Phase I of the study and/or may wish to participate in Phase II, please indicate your email so that I may contact you:
_____

Appendix F- Consent Form for Interviews and Journaling

Dear participant,

You are being asked to participate in a study concerning the professional practice involved in cases of mistreatment of older adults with dementia by a family caregiver. I am interested in learning more about how practitioners, such as yourself, manage cases where older adults with dementia are mistreated by their caregivers in the home. In a larger sense, I want to learn about the forces that come into play influencing your everyday management of these cases. Lastly, I am interested in your challenges as you encounter and contemplate these types of cases, decide upon your interventions, and act in a way that is meaningful to you. This study is conducted within a PhD thesis.

Your participation entails answering open-ended questions in an individual interview session lasting approximately one hour. Funds have also been obtained to rent a meeting room as needed. All participants will be offered both alternatives and preferences will be respected.

These interviews will be audiotaped and transcribed verbatim. Following the interviews, I will request that you reflect further on your experience by commentating in a journal on a few follow-up questions in the format of your choice (electronic or paper format) and return the journal electronically or via prepaid mail within 1 month of receipt.

Participation in this research project is completely voluntary. You have the right to decline to participate. You may change your mind at any time and withdraw. You may choose not to answer questions or to stop participating at any time. Whether you choose to participate or not be disclosed to your employer or supervisor.

All interview data and demographic information collected will be assigned a code number. Your name and the name of your organization will not appear on any information collected except on the research consent form. The shared information will be summarized along with information obtained from other participants.

When the results of this study are published or presented at a research conference, you name and any identifying information will not be used. All individual information will be kept confidential and will not be accessible to persons not connected with the research study.

Transcripts and audio recording will be password protected and stored in a locked filing cabinet in the researcher's locked office, located in the School of Nursing, Laurentian University. Consents will be stored separately using the same precautions. All audio data will be destroyed by recycling once findings are published. All paper records will be shredded then cross shredded after completion of the study.

The sharing of these experiences during the interviews may have a therapeutic effect for you as you share the challenges you have encountered and reflect on what would assist you in your practice. Although as a professional, you may encounter such cases in your everyday work life, sharing of the challenges in this practice might elicit distress. I will conclude each interview by reviewing with you the contact information of the employee assistance program of your organization.

Prior to any data collection, the legal considerations of sharing information regarding OAM must be reviewed. In Ontario, there is no legal responsibility to report OAM as there is no adult protective legislation. However, if, during the course of the interview, you share that an older adult or caregiver is at significant risk of serious bodily harm … violence, suicide, imminent danger, I will review existing pertinent legislation (Canadian Centre for Elder Law, 2011).

As an acknowledgment, you will receive a USB key with resources pertaining to OAM and dementia and outcomes of the action phase of the study. Hard copy interim and final reports will also be produced and disseminated to all participants to share with your organization.

If you have concerns or questions about this study, you may contact me, the student researcher Jeannette Lindenbach from Laurentian University, Sudbury, at 705-675-1151 or toll free at 1-800-461-4030 extension 3824 or at jm_lindenbach@laurentian.ca. You may also reach my thesis supervisor, Dr. Kristen Jacklin, at 705-662-7277 or toll free at 1-800-461-8777, or at kjacklin@nosm.ca

If you have questions or concerns about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact a Research Ethics Officer, Laurentian University Research Office at 705-675-1151, ext 3681 or toll free at 1-800-461-4030 or email ethics@laurentian.ca

(**For organisations under HSN information letter add**: Your Rights as a Research Subject: If you have any questions regarding your rights as a research participant, you may contact the Health Sciences North Research Ethics Board at 705-523-7100, ext. 2409 or by email: reb@hsnsudbury.ca. The Research Ethics Board is a group of people who oversee the ethical conduct of research studies. These people are not part of the study team. Everything that you discuss will be kept confidential.)

Your signature below means that you voluntarily agree to participate in this research study.

_____	_____
Participant signature	Date
_____	_____
Researcher signature	Date

Appendix G- Interview Guide

Introduction:

Introduce myself: Name, PhD student, Nurse, Past Case Manager

Explain what use will be made of recordings-only used by researcher and identify of participant will not be revealed

Explain focus: "*I am interested in learning more about how practitioners, such as yourself, manage cases where older adults with dementia are mistreated by their caregivers in the home. In a larger sense, I want to learn about the forces that come into play influencing your everyday management of these cases. Lastly, I am interested in the challenges you face when reflecting on your course of action in these cases, deciding upon your interventions, and acting in a way that is meaningful to you".*

Explain that they are free to express opinions, no right or wrong answers

Ask them to introduce themselves-Name, professional history, preferred areas of nursing care

1. Can you describe one of your past cases of mistreatment of an adult with dementia by a family caregiver?

Prompts:

Characteristics of older adult
Characteristics of caregiver
Home-rural, urban-isolation
Informal support system
Formal care
Interventions
Challenges
Opportunities
Outcomes
Approximate year of case

2. At the time of that case, what knowledge guided you in deciding on your interventions?

Prompts:

Past education-undergraduate, inservices

Organizational Policy and procedures, decision trees

Managerial guidance

Regulatory body guidance

Legal context in Ontario-capacity, confidentiality, reporting

Intuition

3. As a _____ (nurse, SW, counsellor, clinician, supervisor), you use many sources of knowledge to make your decisions. In this case, can you think of other factors that influenced your decisions?

Prompts:

Professional

Personal

Ethical

4. In cases of mistreatment, there can be multiple influences on the decisions we make. What or who are factors in your decision making process in these cases?

Prompts:

In the home

As an employee with _____

In my rural or urban community

Home care

Society

5. Let us change focus somewhat. With your case, can you describe for me how you felt during the course of this case, from the moment you suspected mistreatment to the eventual discharge from services?

Prompts:

Suspicion of mistreatment

Identification

Interventions

Discharge from services

6. Can you describe for me how you felt about your ability to intervene in this case?

Prompts:

Ability to choose interventions

Degree of confidence in chosen interventions

Feeling of competence

7. Many authors, in books or articles about OAM, state that practitioners "should, ought to, must" intervene in these cases. What is your reaction when I read that statement about expectations of practitioners such as yourself?

Prompts:

Thoughts

Feelings

Beliefs

8. To you, as a _____ (nurse, SW, counsellor, clinician, supervisor), what does it mean to intervene in a "meaningful way" in these cases?

Prompts:

In link with professional values

For the mistreated older adult

Important outcomes of a case

9. I have one last question for you. In a perfect world, what would you need to intervene in these cases in a way that was important to you?

Prompts:

Formal services

Informal services

Knowledge

Infrastructure

10. Is there anything else you would like to add or discuss?

Conclusion:

I want to thank you for your valuable contribution to understanding this experience and to assure you that confidentiality will be maintained with your consent form and recording.

Here are the next steps of the study:

I will be listening to your transcript and preparing a few questions to send you as a form of journal. These questions will allow me to understand more deeply the factors impacting your professional management of these cases within your everyday work context. The journal will be in the form of an email or paper format with further directions attached. Would you like to continue to participate by receiving and completing a journal?_____ What format would you prefer? _____

Once I receive that, after a few weeks, I will analyse all of the interviews and journals. A summary of this analysis will be shared with you in a few months via email, as well as that of my Phase I findings. At that point, as this project aims to improve professional practice, I will invite you back, if you wish, to Phase II, where practitioners who want to effect change will work together on a project they feel would be beneficial to OAM professional practice in their geographical area.

I look forward to continuing to work with you, if you choose to do so. Do you have any questions about the interview or the steps to come?

Appendix H- Reflective Journal Guide

Case scenario: Try to imagine the following situation. Details are purposefully omitted so as not to influence your answers. There are no right or wrong answers. Your responses will be summarized with those of the other participants and confidentiality will be maintained.

The professional managing the care for an older adult suffering with dementia has been suspecting mistreatment by the family caregiver for some time. The home is in _____ (rural, urban) Ontario. The mistreatment consists of physical negligence and psychological abuse. Literature with other practitioners illustrate that intervention can be viewed on the following continuum of care:

Protection----------Accompaniment----------Silence/File closure

1. In general, which part of the continuum, (Protection, Accompaniment, /Silence/File closure), more closely reflects your interventions in a similar case? Provide as much detail as possible.

2. What resources could you turn to to help you in this case? These can be professional, within your organisation, your community, the law, society, or personal.

3. In these cases, are there "taken for granted" rules or "traditional" rules to follow?

4. Can you think of powerful factors, those that others who do not have your professional responsibility would be unaware of, that would influence your ability to manage this case?

5. What would your organization expect from you in this case?

6. What would society expect from you in this case?

7. Can you reflect on what would be important to you in this case?

8. What feelings do you have about cases such as this one?

9. Have you ever found yourself in a similar situation where you had to make a decision about how to intervene along this continuum? Can you describe your personal beliefs about this?

10. What changes need to occur to empower you with these cases? (at the professional practice level, at your organization, in home care, in legislation, in society)

Appendix I- Consent Form for Focus Groups-Inquiry

Dear participant,

You are being asked to participate in a study concerning the professional practice involved in cases of mistreatment of older adults with dementia by a family caregiver. I am interested in learning more about how practitioners, such as yourself, manage cases where older adults with dementia are mistreated by their caregivers in the home. In a larger sense, I want to learn about the forces that come into play influencing your everyday management of these cases. Lastly, I am interested in your challenges as you encounter and contemplate these types of cases, decide upon your interventions, and act in a way that is meaningful to you. This study is conducted within a PhD thesis.

Your participation entails participating in a focus group lasting approximately two hours. This focus group will be audiotaped and transcribed verbatim. The regional consultant will co-facilitate the focus group discussions. Your traveling costs to a central location for the group, at a rate of 55¢/km, will be reimbursed and a light lunch provided. Funds have been obtained to rent a meeting room for focus groups as needed.

Participation in this research project is completely voluntary. You have the right to decline to participate. You may change your mind at any time and withdraw. You may choose not to answer questions or to stop participating at any time. Whether you choose to participate or not be disclosed to your employer or supervisor.

All interview data and demographic information collected will be assigned a code number. Your name and the name of your organization will not appear on any information collected except on the research consent form. The shared information will be summarized along with information obtained from other participants.

When the results of this study are published or presented at a research conference, your name and any identifying information will not be used. All individual information will be kept confidential and will not be accessible to persons not connected with the research study.

Transcripts and audio recording will be password protected and stored in a locked filing cabinet in the researcher's locked office, located in the School of Nursing, Laurentian University. Consents will be stored separately using the same precautions. All audio data will be destroyed by recycling once findings are published. All paper records will be shredded then cross shredded after completion of the study.
For focus groups, confidentiality cannot be guaranteed if participants choose to speak outside the context of the research. The importance of maintaining confidentiality will be discussed at the beginning and conclusion of each group session.

The sharing of these experiences during the interviews may have a therapeutic effect for you. Although as a professional, you may encounter such cases in your everyday work life, sharing of the challenges in this practice might elicit distress. I will conclude each focus group by reviewing with you the contact information of the employee assistance program of your organization.

Prior to any data collection, the legal considerations of sharing information regarding OAM will be reviewed. In Ontario, there is no legal responsibility to report OAM as there is no adult protective legislation. However, if, during the course of the interview, you share that an older adult or caregiver is at significant risk of serious bodily harm … violence, suicide, imminent danger, I will review pertinent existing legislation with you (Canadian Centre for Elder Law, 2011).

As an acknowledgment, you will receive a USB key with resources pertaining to OAM and dementia and outcomes of the action phase of the study. Hard copy interim and final reports will also be produced and disseminated to all participants to share with your organization.

If you have concerns or questions about this study, you may contact me, the student researcher Jeannette Lindenbach, from Laurentian University, Sudbury, at 705-675-1151, or toll free at 1-800-461-4030 extension 3824 or at jm_lindenbach@laurentian.ca. You may also reach her thesis supervisor, Dr. Kristen Jacklin, at 705-662-7277 or toll free at 1-800-461-8777, or at kjacklin@nosm.ca

If you have questions or concerns about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact a Research Ethics Officer, Laurentian University Research Office at 705-675-1151, ext 3681 or toll free at 1-800-461-4030 or email ethics@laurentian.ca

Your signature below means that you voluntarily agree to participate in this research study.

_____ _____

Participant signature Date

_____ _____

Researcher signature Date

Appendix J-Vignette for Inquiry Focus Groups

Mrs. J. is in the middle-stage of Alzheimer. She lives in her home in rural/urban Northeastern Ontario (choose the context you are familiar with). In addition to her cognitive decline which challenges her capacity to make her own care and financial decisions, she has recently suffered a hip fracture which became infected post-surgery. Upon hospital discharge, the following community services were set up by CCAC: Nursing daily for wound care, monitoring; Physiotherapy for mobility; Occupational therapy for activities of daily living, and personal support worker for daily personal care. In addition, the Alzheimer Society and Behavioural Support Ontario have been providing consultation and resources related to Mrs. J's cognitive decline. With these services, and the healing of her hip, Mrs. J. is progressing well and services are decreasing in frequency.

Recently, Mrs. J's son moved in with her as he lost his job. The service providers begin reporting the following: empty medication bottles, missed follow up medical appointments, Mrs. J. appearing nervous when son involved in discussions with service providers, inability to speak with Mrs. J. without the son's supervision, very little food in refrigerator, and some weight loss. Mrs. J.'s cognitive status is declining and the service providers are increasingly worried about her well-being and some are becoming fearful of the son's reported threatening demeanour. Last week, the police were called by a concerned neighbour who reports hearing Mrs. J. screaming. On arrival at the home, Mrs. J. denied any wrong doing by the son and insisted she is happy in her own home.

There is a daughter who lives out of town and holds the power of attorney for personal care and financial decisions. Although seemingly caring, she reports being overwhelmed with her own responsibilities and cannot understand why more community services cannot be put in

place to care for her mother. When a move to a retirement home is recommended, it is discovered that there are insufficient funds remaining in Mrs. J's savings.

Mrs. J's son has now begun declining in home services stating his mother is doing much better and doesn't need all of these "interruptions from nosy people". The CCAC care coordinator contacts you. She states she is treading very carefully trying to keep services in the home without upsetting the son who will refuse services altogether. She asks you: "What can I do?"

Appendix K- Focus Group-Inquiry Guide

Case scenario: Try to imagine the case scenario provided. Details are purposefully omitted so as not to influence your answers.

1. In your geographical area, what resources exist to assist a professional in this case? (These can be professional, within your organisation, your community, the law, society, or personal).
2. Do you believe there are "taken for granted" rules or "traditional" rules that practitioners follow in these cases?
3. Can you think of powerful factors, that those without your expertise, would be unaware of, that would influence a professional's ability to manage this case?
4. What would society expect from a professional in this case?
5. What feelings do you have about cases such as this one?
6. When you are called upon by practitioners in the field for similar cases, can you share some primary concerns voiced by practitioners?
7. What changes need to occur to empower practitioners with these cases? (at the professional practice level, at your organization, in home care, in legislation, in society)

Appendix L-Interim Report

Connecting stakeholders in Northeastern Ontario to collaboratively act on barriers and opportunities to address OAM in cases of dementia: A two phase study

Acknowledgments

This Interim report, with findings from Phase I of the study, presents the rich experiences of 51 practitioners who strive to make a positive difference in the lives of older adults and their caregivers every day in Northeastern Ontario. It is thanks to them that we learn about challenges, successes, and hopes for the future for OAM and dementia in the home context. I am incredibly grateful to them for sharing with me their time, experiences, and expertise. I also acknowledge the support received from their employers who recognized the importance of their participation in this study.

This study is a collaboration with *Elder Abuse Ontario*, and particularly, a partnership with Josée Miljours, the Regional Coordinator for the Northeastern Ontario region. Josée has been instrumental in providing resources, knowledge, liaison opportunities, and frequent encouragement.

This study is generously funded by the Ontario Trillium Foundation.

Table of Contents

Background

Older adults are more frequently victimized by their adult children or spouses, with rates as high as 85-90%

When older adults are mistreated, practitioners involved in their care are entrusted by society to intervene. The professional duty to act is intensified when additional factors such as dementia, mistreatment by a family caregiver, geographical isolation, and the hidden home setting increase vulnerability. However, when practitioners are confronted with mistreatment, their agency, the "human capacity for reflective action and choice" (Frie, 2011, p. 341), is challenged by many factors not only within the home but also within the professional, the institution of home care, and the larger socio-legal context (Killick & Taylor, 2009; Norris, Fancey, Power, & Ross 2013).

1.1 OAM

OAM is defined as "actions and/or behaviours, or lack (thereof) that cause harm or risk of harm within a trusting relationship" (National Initiative for the Care of the Elderly, 2012, p .99). I have chosen this definition as it most closely represents the mistreatment which occurs between an older adult and their family caregiver in the home setting with whom there is a trusting relationship. This definition is also most appropriate given the added vulnerability of dementia and the isolation that can occur in a rural context.

1.2 Dementia

Numerous factors motivated my choice to focus on older adults with dementia. Studies have discovered that when an older adult has dementia, prevalence rates are approximately ten-fold those of the general population: from 4% (Podnieks, 1992) and 8.2% (McDonald, 2015) to 45% to 55% (Cooney, Howard, & Lawlor, 2006; Wiglesworth et al., 2010). Given these alarmingly high prevalence rates, practitioners must be cognizant of the increased risk for these older adult/family caregiver dyads. In addition, these cases present complexities of dependence on a mistreating caregiver, cognitive capacity challenges and potential ageism (Beaulieu & Leclerc, 2006; Phelan, 2008). Also, due to ethical challenges, most studies and intervention guidelines exclude older adults with dementia. Lastly, dementia may represent a more important challenge in the rural context; in a Saskatchewan study, among those aged 85 years and older, the unadjusted prevalence rate of dementia was 13% higher among rural than urban residents (Kosteniuk et al., 2015). Therefore, older adults with dementia in a rural context are a particularly at-risk group, where professional agency is further challenged, and of which we know very little.

1.3 Family caregiver

A family caregiver is an individual from the older adult's informal support network who provides the majority of care. The notion of family caregiver was chosen due to the pivotal relationship in home care where responsibility for care or protection has been assumed by the "caregiver" (National Research Council [NRC], 2003). However, research has repeatedly demonstrated that older adults are more frequently victimized by their adult children or spouses, with rates as high as 85-90% (Amstadter et al., 2011; Choi & Mayer, 2000; Friedman, Avila, Tanouye, & Joseph, 2011; NRC, 2003; Weeks, Richards, Nilsson, Kozma, & Bryanton, 2004). The caregiver, gatekeeper to the home, may also refuse services (Beaulieu & Leclerc, 2006; Fitzsimons, Hagemeister, & Braun, 2011; Omote, Saeki, & Sakai, 2007). Those at greatest risk of mistreatment are frequently the most isolated and at-risk older adults who are shielded by their abuser (MacKay-Barr & Csiernik, 2012; Weeks et al., 2004).

1.4 Rural context

The decision to focus on the rural context was based on a number of considerations. Firstly, in rural Northeast Ontario, the proportion of older adults is projected to increase from 18% to 30% by 2036 (North East Local Health Integration Network [NE LHIN], 2012). Next are risk factors for OAM such as isolation frequently encountered in rural settings (Dimah & Dimah, 2003); outmigration of caregivers which can cripple the informal support system (Fitzsimons et al., 2011; Statistics Canada, December 2012); financial dependence of the caregiver on the older adult, a concern in rural areas where loss of employment and lack of education are common (Amstadter et al., 2011; Desmeulles & Pong, 2006); and the reluctance of some rural older adults to accept formal health services (Harbison, Coughlan, Karabanow and VanderPlaat, 2004, 2005). Lastly, as most studies are conducted in urban centers, understanding of contextual rural risk factors and its professional care are greatly reduced (Amstadter et al., 2011; Cornes, Manthorpe, & Haselden, 2010; Harbison et al., 2005).

1.5 Professional agency

The definition of agency for this study reflects the overwhelming experience of facing a case of OAM compounded by dementia. Frie (2011) defined agency as: "an emergent, affective, and cognitive process that permits us to respond to our situations in meaningful ways" (p. 341). It also speaks to the serious and sometimes fatal outcomes of decisions taken in these cases, the ethical dilemmas faced, and the influence of policy on decision-making. Lastly, "when persons have no voices other than prevailing discourses in which they exist, not only is agency dismantled, the possibility of social, political, and psychological change is undermined" (p. 348). I believe that a lack of professional agency is reflected in the handful of studies that have explored professional decision-making in cases of OAM: practitioners frequently do not know how to proceed and may simply not intervene (Beaulieu & Leclerc, 2006; Omote et al., 2007). To my knowledge, no study has explored the professional's sense of agency when older adults with dementia are mistreated within their homes.

Study Design and Methods

Ethical approval was received from Laurentian University as well as from the ethics committees of participating organizations.

2.1 Sampling

Five Northeastern geographical districts were reached via this study. Sampling aimed to obtain a purposive sample of practitioners willing to share their experience of agency in a past case of an older adult with dementia mistreated by their family caregiver. Assistance to distribute the invitation was provided by the management of 5 community health care and social services organizations in Northeastern Ontario.

Phase I interviews continued, taking one of the five identified regions at a time, until saturation was reached: "when the same stories, themes, issues and topics are emerging from the study subjects" (Bowling, 2009, p. 410). Phase I focus groups were held in each of the geographical districts. A sufficient number of interviews and focus groups was required to obtain thick and rich data sets. This would ensure validity as variation and depth of analysis are made possible (Morse, 2015). It also contributed to internal reliability as key issues resembled each other in the data and permitted me to see the replication.

Phases and methods

In Phase I, the goal was sharing of past experiences of OAM and dementia. In-depth semi-structured interviews aimed to understand the embedded meaning of the professional experience of agency (Carter & Henderson, 2005).

Despite the benefits of interviews for data collection, participants might only reveal their "public accounts" and not share their "private accounts" which include true feelings and beliefs (Bowling, 2009, p. 409). Therefore, a reflective journal was added to supplement the interviews.

Phase I also aimed to further understand the context within which practitioners are embedded. Focus groups permitted a discussion with practitioners in the larger context. In this phase, members of existing Northeastern Ontario networks participated in key informant focus groups.

2.3 Analysis

As a qualitative researcher, I have immersed myself in the data, aiming to understand the reality of my participants. Each word, sentence, paragraph, what is repeated, and what is omitted, are all reflected upon. I then consider the interview and focus groups amongst the others and make linkages with data from other participants, looking for common themes and important differences. In this report, a descriptive analysis is provided. A more in-depth thematic analysis will be completed prior to publication of findings in the scientific literature analysis (Braun & Clarke, 2006; Tuckett, 2005).

3. Findings

3.1 Participants

Fifty-one practitioners participated in Phases I and II. There backgrounds were varied: nursing, social work, gerontology, recreational therapy, psychology, physical education, business administration, criminology, and corrections.

Overall, 23 Ontario organizations were represented. We were also fortunate to have retired volunteer members who continued to participate in the study.

3.2 Phase I: Interviews and Reflective journals

Twenty-eight 1-1.5 hour-long interviews were conducted, transcribed, and analyzed using NVivo11 software. Reflective journals were prepared for each participant based on the content of their transcript. Findings are organized into categories or themes, supporting verbatim is offered, and interpretation is offered. An effort has been made to anonymize any personal information.

Revealing/Distressing intimacy of the home context.

Findings revealed the privileged position of practitioners who were able to access the home environment as is was very revealing of concerns that would not have been seen otherwise. It permitted to witness the interaction between the dyad, sometimes power, or fear. This intimacy could be very distressing however, and those who were not privy to this context, could remain removed and untouched by the mistreatment.

This resulted in frustration for those who were closer, or intimate with the dyad, who expressed sometimes feeling unheard by others. The home context was also described as an uncontrollable context where the mistreating caregiver controlled the situation.

This notion of power and control has been identified in the literature (Grama, 2000; MacKay-Barr & Csiernik, 2012; Weeks et al., 2004).

Caregiver characteristics.

In the presentation of cases experienced, three profiles of caregivers developed: malintent, unclear, and caregiver stress.

Malintent.

It is morally challenging to realize that family caregivers can mistreat the older adults in their care, especially in cases of dementia. Practitioners traditionally "care for" and this realization is not a natural process. Sometimes, when reflecting over the course of the interview, practitioners might pause, having to question their own assumptions. Unfortunately, numerous cases of mal intent were shared. It is interesting that, even when given a case scenario of a definitive case of malintent in reflective journals, many practitioners questioned the possible stress level of the caregiver. Supportive interventions to address caregiver stress were easily listed; protective interventions in cases of malintent were more challenging. The following Wordcloud depicts the most frequently used words in the description of these cases.

*"**Going to the home set off a bunch of alarms**…because of **his stature standing** there when we are asking her questions. And how it would escalate and he was answering for her. We could see it at every visit we went…and he was just a little higher strung…very paranoid and **she would be clamped down** …So, yes the lights all went off…"*

*"some people I will be very worried about…. with the doctors I have, not fought with them but had discussions…I am very worried and they are not. **But they are not going in the home**, right".*

*"It's **sad to see** what you see sometimes when you go into certain homes".*

*"he was isolated from primary supports…trying to get into the house was incredibly difficult. And when you got in, **one day he had a gun, a toy gun because he was so scared; knives at the door, I mean so risk is far greater,** right".*

*"Yes, so in the end, the only plan that we could come up with was him ending up in hospital was the best thing. Because **he***

Unclear.

In some cases, practitioners were unsure of the intent of caregivers. They questioned their level of knowledge with dementia, if they realized their behavior would be considered mistreatment, or if their own challenges with substance abuse, mental illness, ineffective coping contributed to the mistreatment.

Compassionate fatigue.

Interestingly, in the literature, doubt has been cast over caregiver stress as a risk factor for mistreatment (Buckwalter et al., 1996). Some do acknowledge that caregiver stress creates a « fertile ground » (Chokkanathan, 2014). This may stem from the fact that as consent is required for participation in research, the vast majority of studies are conducted with older adults without cognitive impairment; this risk factor has therefore not been sufficiently tested.

Most large quantitative studies that provide statistics have a cognitive test as part of their eligibility criteria. Therefore, when looking at risk factors, those researchers are able to examine their sample and determine that caregiving stress is not a risk factor. However, the participants in this study clearly described compassionate fatigue as a risk factor for mistreatment; past cases and worries for current cases were reported.

"it becomes too much to do it all. That's when the ***caregiver becomes at-risk and at risk of potentially harming****…they tell us, I can't do this anymore, I need more help and we try to avoid hospital admissions* ***but sometimes, the risk is too high*** *because of the limitations of services…the caregiver is really tapped out and cannot do this anymore. ..ninety percent of the times, caregivers give it their all…by the time they tell you this, they have done everything they could. Whether its crisis placement, or hospital admission. Because people can only do so much".*

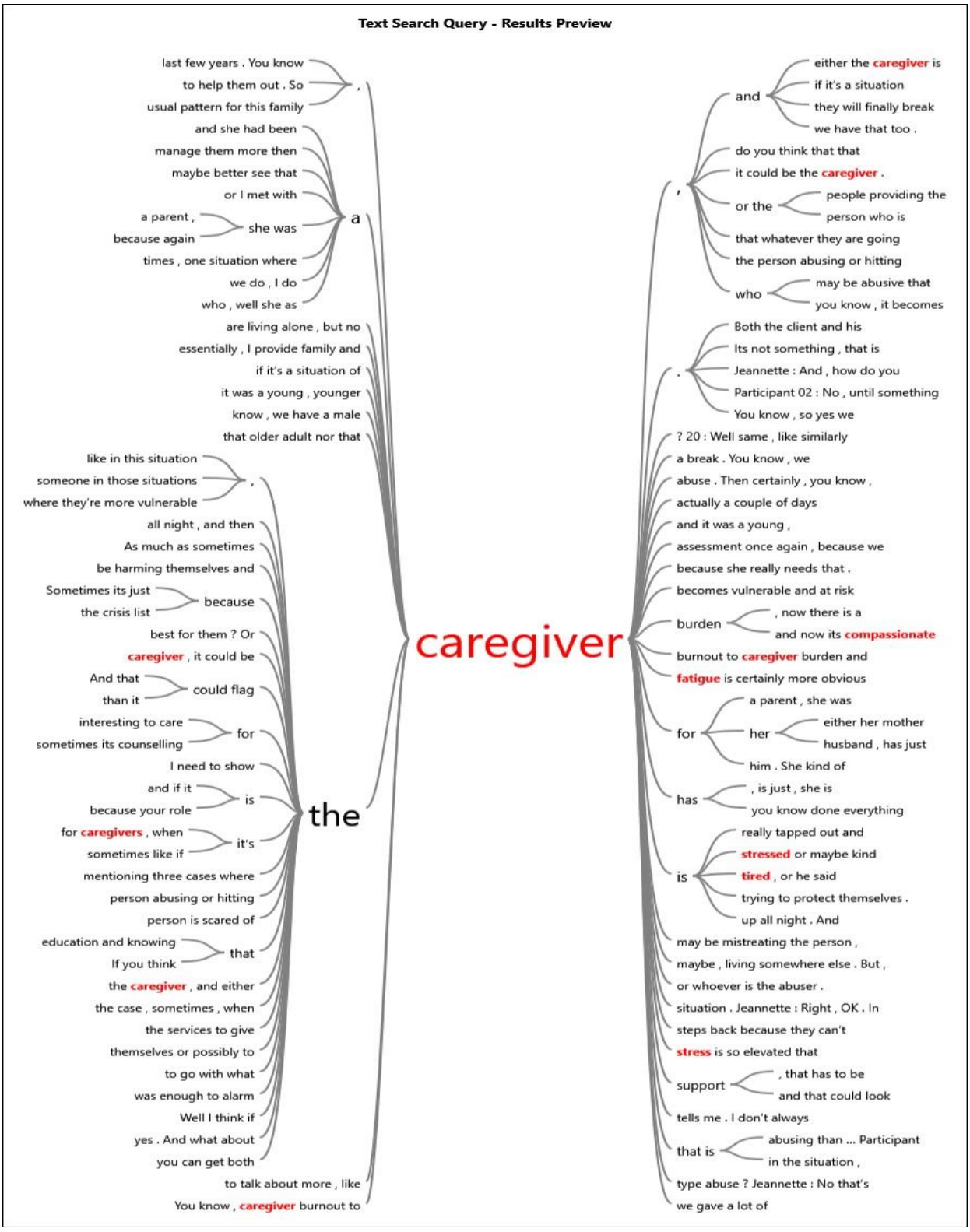
"caregivers get so overwhelmed and burned, they do get to a point where they are short tempered, ***that's when the yelling comes in****".*

"One lady said: ***I would see my mom's phone number and I just wanted to start screaming and swearing****. Because you have just talked to them four minutes ago, and they woke up at five in the morning and they start calling you at five in the morning. And then they forget they called you and they call you again. So, that's where if you don't help them understand this disease, that is where the abuse starts. And it is not intentional abuse, it's either hanging up on them, screaming at them or something.* ***Because you are so frustrated you have no answer for it****".*

"Care givers don't realize how harsh or sharp *they can be with the family member and there is some definite emotional abuse taking place for sure".*

"there could be a stage in the ***development of dementia as it progresses****, that they have sun downing where they are up all night, and then the caregiver is up all night and they may not be able to sleep during the day. So, those situations, we keep a closer eye on those situations because they can burn out very quickly".*

The following Word Tree provides some context of caregiver stress discussions:


Text Search Query - Results Preview
caregiver
the
last few years . You know
to help them out . So
usual pattern for this family
,
and she had been
manage them more then
maybe better see that
or I met with
a parent ,
because again
she was
a
times , one situation where
we do , I do
who , well she as
are living alone , but no
essentially , I provide family and
if it's a situation of
it was a young , younger
know , we have a male
that older adult nor that
like in this situation
someone in those situations
where they're more vulnerable
,
all night , and then
As much as sometimes
be harming themselves and
Sometimes its just
the crisis list
because
best for them ? Or
caregiver , it could be
And that
than it
could flag
interesting to care
sometimes its counselling
for
I need to show
and if it
because your role
is
for caregivers , when
sometimes like if
it's
mentioning three cases where
person abusing or hitting
person is scared of
education and knowing
If you think
that
the caregiver , and either
the case , sometimes , when
the services to give
themselves or possibly to
to go with what
was enough to alarm
Well I think if
yes . And what about
you can get both
to talk about more , like
You know , caregiver burnout to
,
and
either the caregiver is
if it's a situation
they will finally break
we have that too .
do you think that that
it could be the caregiver .
or the
people providing the
person who is
that whatever they are going
the person abusing or hitting
who
may be abusive that
you know , it becomes
.
Both the client and his
Its not something , that is
Jeannette : And , how do you
Participant 02 : No , until something
You know , so yes we
? 20 : Well same , like similarly
a break . You know , we
abuse . Then certainly , you know ,
actually a couple of days
and it was a young ,
assessment once again , because we
because she really needs that .
becomes vulnerable and at risk
burden
, now there is a
and now its compassionate
burnout to caregiver burden and
fatigue is certainly more obvious
for
a parent , she was
her
either her mother
husband , has just
him . She kind of
has
, is just , she is
you know done everything
is
really tapped out and
stressed or maybe kind
tired , or he said
trying to protect themselves .
up all night . And
may be mistreating the person ,
maybe , living somewhere else . But ,
or whoever is the abuser .
situation . Jeannette : Right , OK . In
steps back because they can't
stress is so elevated that
support
, that has to be
and that could look
tells me . I don't always
that is
abusing than ... Participant
in the situation ,
type abuse ? Jeannette : No that's
we gave a lot of

Impassable distance between alarm intuition and facts

Participants shared feeling that something was not quite right but not being able to confirm what made them so uncomfortable. This notion of basing decisions on intuition and vague cues was revealed in some 1990's literature (Saveman, Hallberg, & Norberg, 1993, 1996). Many shared the distress caused by the large gap between this intuitive knowledge of something being wrong, and the facts required to prove that wrong. Some also described having to work against the legal system as they felt the system was disregarding their concerns as health care and social services practitioners; the legal system seemed oppressive.

"That kind of ***struck the little question mark or light bulb*** *and that really flagged it and I said no there is something not quite right".*

"still to this day, there are times where you go into someone's home and things don't feel right, and there is just a little something off…and ***your hair stands up on your arms and you think oh my goodness something is going on here but I can't put my finger on it.*** *And then you leave there, and that is all you can think about…it makes you wonder what's really going on there".*

"you have to take whatever is there at face value but as nurses we are trained to notice some things right. But it's ***a very difficult place to be. It is very difficult****".*

"nothing really could get done there ***wasn't enough evidence*** *there for us to really proceed"*

"But to prove that it takes a lot. And we have had that where we thought there was a situation where there was neglect, and when we went to proceed with the hearing we did not have enough information. And that's, the ***legal system versus the health care system****, right. Because some of what we do is factual, and we react to the facts. But also,* ***there is gut, right, and instinct. So, that doesn't go anywhere with the legal system****. So, you really need complete documentation, facts and often hearsay is not often accepted in the legal proceedings".*

"like in a hearing for example, the ***lawyers are there to prove we did something wrong****, whether it's you forgot to document this (…) Because we do everything based on the client's best interest. So, and not that the lawyers don't think that way, but there's is to protect that patient. They are hired to say, you know what you prove to me why you think that they are at risk, or they are at-risk, or there is neglect"*

Family sanctity.

These experiences presented the added complexity of a phenomenon occurring within a family of which practitioners were an outsider. Practitioners shared how this barrier prevented access to the older adult who sometimes lacked insight to protect themselves. Numerous cases of abuse of power of attorney were shared revealing some powerlessness. The isolation, constant supervision and control over the older adult by some family caregivers was an added layer of complexity when dealing with OAM within the family context. This control over the family context by a mistreating caregiver has been identified in the literature, although not specifically to older adults with dementia (Beaulieu & Leclerc, 2006; Fitzsimons et al., 2011; Omote et al., 2007). Practitioners did not want to pry into the sanctity of the family, especially when the older adult with dementia was struggling with feelings of loyalty towards their caregiver. This professional explains how delicate the therapeutic relationship had become due to manipulation by the caregiver: *"I was hurt because how do you tell somebody that your son isn't the person that you think he is. You can't do that. ...**with dementia, you can't argue with them, you can't change their way of thinking**. Because what they feel is going on, you can't change that. And no matter what he was still her son, it was I think easier for her to believe that I was, at that moment, I was the enemy and not her own flesh and blood".*

*"Like **she (police officer) had huge concerns but they said there wasn't much they could do. Because he (older adult with dementia) was agreeable for them (mistreating sons) to be there**".*

*"**families have different dynamics and it can be daunting to try to get in the middle**. And say no, no, no this is the right way to do it, what you are doing is wrong".*

"So, you suspect something, but the families, they hide that".

*"I felt that we had to try to get her out of that current situation as soon as possible. Of course, power of attorney was the person that she was scared of. **There is not a lot that I can do…. realistically, he is the power of attorney**".*

*"**However, her power of attorney was her son**. So, we were shooting herself in the foot if we made her incapable"*

*"he had her up, on the upstairs apartment, above, on the second floor. So, it was difficult to get her out. So, that was, like the **seclusion** was there as well".*

"But it doesn't seem like there is a lot of information out there. ***There are no rules,*** *(…) I want to know what the parameters are, and whose job it is. And what I actually have to do".*

*"****everyone was kind of like, nobody knows. Nobody knows what to do. That's not ok****".*

"I still feel like I am going to struggle with what's within my sort of scope. What am I allowed to do?"

"like ethically and professionally what do I do at this point? And again, ***just call police and flag it and then that's about it"****.*

*"****I think for someone who is demented we have an obligation to do something, an obligation, I don't know if it's a legal obligation. But I do think, we do have to help that person****".*

Professional duty. Practitioners searched for rules to follow and expressed frustration about not knowing what could be done, by themselves as well as their team members. This notion of professional duty was intensified in cases of dementia.

This intellectual exercise was then further complicated when, in the absence of legal and professional guidelines, a moral exercise ensued; of at least doing something, even if not what could be done according to the laws, instead of doing nothing.

This lead to some rule bending. This exercise however, was more remarkable with practitioners who had dealt with many cases of OAM and dementia. Those with limited exposures were more rule-based.

Only a handful of studies that have been conducted in similar legal contexts as Ontario, as most studies in this field are conducted in contexts where duties are clearer (Japan (Omote, et al., 2007), Scandinavia (Erlingsson et al., 2012; Saveman et al., 1993), Quebec (Beaulieu & Leclerc, 2006; Lithwick et al.,1999)).

Moral duty.

For those practitioners who had more exposure to these cases, it became more of a question of "What should I do? and What I want to do?". The experience gained actually lead to more questioning versus having the answers. Moral values precipitated action which sometimes felt quite enormous and lead to further questioning about either actually wanting to take this on, or bending the rules for a more favourable outcome.

"(the) patient was becoming much more impaired…but again how do you intervene. He says no, I am OK, he wanted to go home, he is happy being at home and OK with paying for the family. So, again, ***we don't feel it's appropriate*** *because none of them are working and this and that, but yet do we intervene? Do we have a right to intervene, and in that case?* ***I don't think we do. I don't think we do, but… its tough****".*

"I think as a health care practitioner we do have, how do I say that, well I think we have some responsibility to actually do something, right. I mean, and that's, that's not necessarily even professionally, ***I think personally, that I would feel like I should be doing something****".*

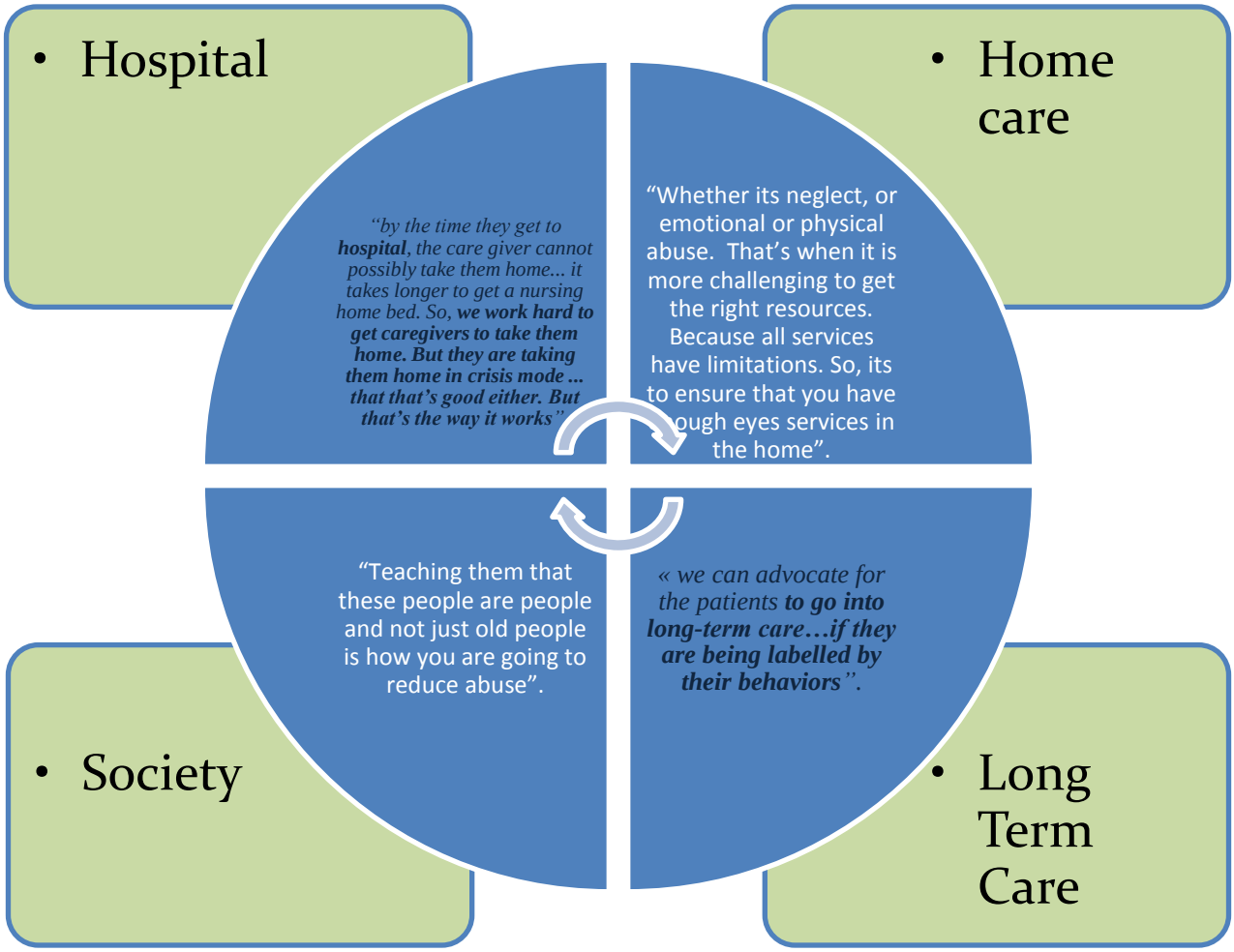
"It is ***more of a moral code for me*** *than it is more than it is a professional code. But that being said that I would hope that professionally I would also. I think morally and professionally I would have to report, that is just me. It is just an easier way for us to get there, take on what is going on …****Morally I will probably have an issue with it".***

*"****You do things that, you know, really are not in your job description****. Or maybe you go over and above* ***because you do care. And you can't just walk awa****y and you know. I think it is just in our profession, we are there to help and to care about people". "Someone to take that responsibility…****because none of us want to. And it's not that we don't want to, don't get me wrong. It's just we don't really know in which capacity to do it. And then if we do, are we going to court? (the) list goes on and on. And I mean, if we have to, we have to, but realistically is that our role? It's big feet for anybody, so I don't know****".*

*"****always difficult, always difficult because I think that we want so badly to protect*** *the individuals as much as we possibly can".*

Systemic challenges.

Challenges to this experience occurred throughout the health and social care continuum: within home care, limitations to care provided inadequate monitoring of the mistreatment, the eyes in the home or difficulties making people fit as per the eligibility criteria; in hospital, one professional whose role had her cover home transitional care from hospital shared her dilemma of having to get older adults with dementia and their exhausted caregivers back into the hospital due to pressures there although she knew it was risky; other participants shared obstacles faced in getting these older adults to a safer place in long-term care related to some behaviours exhibited with dementia. Lastly, some spoke of ageism in our society which permits mistreatment on a systemic level.



Northern-Rural regions.

Those practitioners working in both northern and rural regions covered very large geographical areas, up to a five-hour drive. Some coverage expectations were simply not reasonable, and although practitioners realized that, they still expressed some guilt of not visiting the area frequently. Winter driving conditions frequently closed these northern highways, and in the most northern rural towns, travel to the remote areas was postponed until road conditions were better. Another option was to conduct the visit using OTN technology, although it wasn't ideal with dementia. With limited human resources in these areas, some practitioners played dual roles of educator/clinician. Services, including professional and personal support services were very limited. The strong advantage noted in these smaller towns was the presence of strong formal networks. Practitioners knew the other practitioners and all worked together for better outcomes.

Frustrations. Many frustrations were shared: the notion of the burden of maintaining professional secret was explained and the resulting weight of these concerns, sometimes coming from police, or family, or in many small towns, neighbours; next is the concept of circle of care which saw some reluctance and doubt of intentions of individual members of the team. The notions of capacity assessment as well as working with the PGT were perceived as being impossible as the legality of both aspects seemed overwhelming and at odds with the caring and protective values of the participants.

Professional secret burden

"I was privy and I knew that he was leaving them at-risk and there was a risk level there. That really resonated with me and I had a hard time, you know. What do I do? I think it would be nice to be able to ***because there are some people in the community, elderly specially with dementia that you really worry about. And if you could tell it would be, in a way it would be good*** *to be able to tell the police kind of what is going on.* ***But we really can't say anything. But we couldn't share, we couldn't tell the police anything about the patient.*** *But they could, they report to us"*

Circle of care

"Everybody is like no that is your job, that is yours, no, no we are not getting involved in that. ***The challenge is that reluctance to want to step in, absolutely.*** *We need to pull together as a team and not let one person take the breath of the work. People are very reluctant to get into a dicey situation, that there is going to be some potential for this not going to be pleasant".*

"sometimes we try and go in at the same time, and sometimes we have to get supervisors involved to go in

Fear: Shattering the broken glass. Numerous practitioners shared their fear of increasing risk for the older adult, that professional action could result in loosing access to the home, negative consequences, of fear for the older adult once the professional left the home and of the inability to protect the older adult. Practitioners described treading very carefully in very precarious situations.

Overwhelming nature of encounter.

- *"But accusing them if someone is really worried and scared and they would close the door. Instead of saying ok well he has a bruise on his leg here what happened? And we have had those situations where you know people had, for example, had asked me to go see this patient who had bruises. And they were worried that the daughter was, you know abusive. And so, you can't go in there and say ok I want to see her bruises and show me. I mean that would close the door right away. They would never let you in again. So, you don't want that, you want to keep going".*
- *"how to approach somebody that's supposedly is the abuser, right. Because that day I didn't know how to approach him and… I felt fearful, that she was going to go back into this situation right, after we have spoken to him about her safety and her being scared".*
- *"So, you kind of, it leaves you with a bad taste in your mouth. Because you know there is a problem, you want to fix that problem but the things you need to do to fix that problem are going to cause them more problems at the end of the day. So, you're kind of caught like what do you do".*
- *"in some situations, you think I don't really want to say too much because I'm, I can get out of there pretty quick but I don't want to cause more problems for the patient afterwards".*
- *"it's very, very, it's easy to say intervene but it's a very, very hard situation. And especially from a professional point of you, because, you rock the boat, and the patient is still in that same situation and they are going home to that situation. So, unless we can totally bubble the whole situation, you have to take caution when you are intervening. And unless we have an absolute situation today, we need to walk gently. Not saying that we are not going to do anything and not saying that we don't want to do something. But if we don't have those resources to provide for the client then we may be putting them in a worse situation than they already were".*

"I didn't want to alienate myself from them. I feel it's better to have one foot in the door than to be thrown out. So sometimes I think I should be doing that (questioning the abuser), but I don't, I don't want to put the patient at risk of what is going to be the fallout after".

This fear of increasing patient risk is compounded by the sheer overwhelming nature of the mistreatment within the home. Anetzberger (2005) described this encounter as an assault on the senses. However, in addition to sensory stimuli, participants described an emotional and cognitive bombardment of questioning and problem-solving that is occurring during the encounter.

> *"I think for my part, I mean, even though it's not a, like physically I didn't see, you know. It's more of an emotional thing right, you see her crying, you see her hurt, you see her. And it tugs at your heart, you want to be able to do something, even though she wasn't able to say exactly what was going on. I no longer want to be in my current living situation. I am afraid, I am afraid, but can't specifically say what goes on on a daily basis. Like what, was it physical abuse, was it just financial, are you just feeling smothered in that situation. So, I think of course as nurses we want to, we want to fix it right".*

Professional armor. Despite this fear and overwhelming encounter, practitioners remained composed. They hid their fear as this first participant did as she very calmly described the safety precautions she took with this mistreating caregiver. One professional described her relationship with this dyad as a dance during which she carefully sought information. Therefore, despite fears, practitioners maintained a facade when with the mistreating caregiver.

*"**She was (threatening),** when I spoke to her on the phone".*

*"He would really control that as well. **Even the nurse was scared at times** for her safety and for the client's safety. **I did however have my cell phone with me all the time and I had it opened to the dial pad. So as soon as I swiped it open I could call 911 if I needed to… Just the ones with the lights, the alarms go off. I think he is the only one that I have ever been a little leery about being alone**".*

*"But you want the information, you want the relationship, so you try and **do as much as you can by dancing around some of these things**".*

- *"You know, and I even had a patient come in for a friend of hers. And she said **nobody is listening to me, but this person is going to die**".*
- *"I can't do anymore. You can't invade their privacy and their space. And I mean even though they are making decisions that you know are unsafe. **Sometimes it has to end up in a crisis, before something is done.** Because it's not only me, it's the _____sometimes **their hands are tied**. It can be _____, their hands are tied, _____. The only time is, if there is, and what happens is when there is a crisis".*
- *"So, when he ended up in **hospital it was, it was kind of a blessing in disguise because then we could deal with the situation without him being in that environment**".*
- "***crisis list (...) to long-term care. So, if your parent is (...) getting very frustrated and perhaps hitting his wife because he is so frustrated. I have worked in situations like that.** Like turning to physical violence. That could be four hundred days before he gets in. So, I mean, there is just no awareness of that. People don't know what our system is like".*
- *"So, I put her in a crisis situation meaning that the next available bed would be hers and then… (the) power of attorney refused that bed".*

Waiting for crisis.

The notion of crisis was manifested in different forms during interviews. Whether that be concerns received on an older adult's behalf, the hopelessness of having one's hands tied, the blessing of a crisis hospitalization, or the concern of what could happen while waiting for a crisis LTC bed, the notion of crisis was underlying.

Experience-working through. Practitioners, when facing such a case, reflected on many aspects of the situation before ever deciding if this was actually mistreatment. There were 5 in particular, that could sway a professional one way or another: firstly, was **caregiver intent**-although we use the term mistreatment as an umbrella term for forms of abuse and neglect, practitioners usually first made a judgement as to the intent of the caregiver-they were less apt to name it mistreatment if the caregiver was suffering from fatigue or lacked knowledge of dementia-the mistreatment became clearer where the malintent was more evident. The **form of mistreatment** was then looked at-cases of physical mistreatment, were, for the most part, an automatic decision-still, there were some cases of bruising for example, that, were doubted if the caregiver was stressed or the mistreatment not witnessed by the practitioners in the home. Thirdly, the older adult's **behaviors** were considered in making a decision: there was sympathy for the caregiver, and doubt if the information provided by the older adult was factual and accurate. Fourthly was the **ability to prove** the mistreatment-for example, reports by PSWs were doubted and mistreatment such as neglect was deemed harder to demonstrate**.** Lastly, the **necessity of the caregiver** to the plan of care in the home was an influencing factor…if their participation was deemed essential to maintain the older adult at home, some of their actions seemed to be justified.

Caregiver intent (caregiver stress, lack of knowledge, malintent)

- *"the biggest thing I see is care giver burnout…in other positions I have held also…they become impatient, they are at their wits end, they don't know what to do. And a lot of times that can lead to, the something that you may question, is that abuse or not?"*
- *"It was tough (to decide if mistreatment or not) because the wife, I don't know how much she knew and understood".*
- *"I do see it but I see it more from a care giver burnout rather than, rather than any mistreatment, you know what I mean".*

Form and severity of mistreatment

- "He did bruise, but the reports were that he would fall. Like try to get himself out of bed or hit his arm on something. I don't, I didn't have any reports of suspected physical abuses, as far as I remember. I would have remembered that, that I would have remembered".

Older adult behaviors (sympathy, uneasy understanding)

- *"But **there is that fine line**, (…) it's a difficult situation to be in. (…) you understand your client with the dementia, and the reason why they're behaving a certain way. And you understand the family member, because they are finding it difficult to see their parent behaving a certain way".*
- *"I think with dementia, it's even a little bit more important that you take those little key words, I'm scared, I am not doing well. The tears that are coming down the face. I think with the dementia piece, you just have to be a little bit more aware and not just like OK well this is a demented client…. they still have feelings, they still have… So, I think it's difficult. I think abuse and then put the dementia on top of it, it's a little bit more of a difficult".*
- *"with people with dementia is people aren't necessarily sure what's real and what is not…there is that risk that they are reporting to you and you are going to be like, well, is that real, or is that something they sort of come up with, filling in the blanks. ..is it something they are remembering from when they are twenty years old?"*

Proof-demonstrable

- *"there is only so much we can do for financial abuse. As practitioners, we don't know what is going on. It is very rare that… Like personally for me, have I seen anything like that, or known of any financial abuse? because it's behind the scenes".*

Necessity of caregiver

- "*I mean there might have been some rough handling you know transferring from the bed to the commode chair. So, we put things in place for her. …we suggested*

Disbelief/Realization.An element of disbelief was frequently shared, of flooding emotions such as sadness and anger about the necessity of accepting that OAM does occur within families and disbelief that it is allowed to occur as it can be normalized by society. The professional had to move beyond this disbelief to actually realize the mistreatment was a reality.

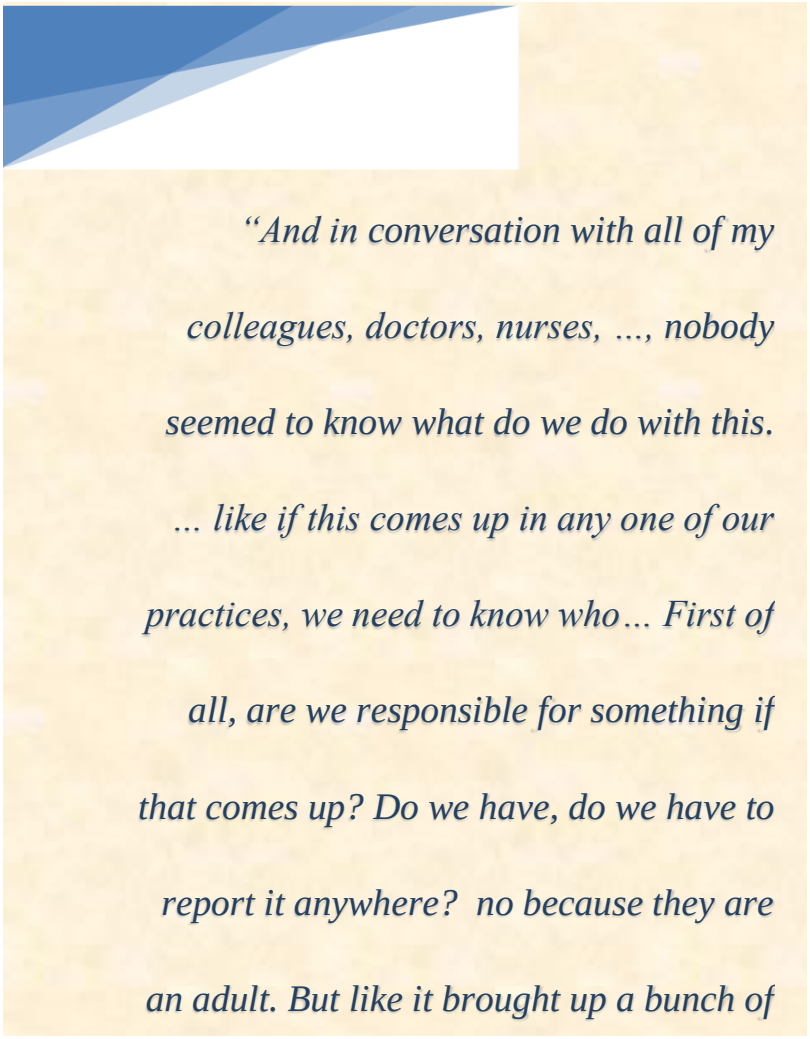
> *"there is **always that sense of anger that one can do this**. My whole career has been in geriatrics. And so, it's my love, it's my passion. So, when I hear stories or when I am involved in situations like that, there is **a whole ray of emotions for me where its sadness, anger, its all of those things that just come across your mind**. So, sometimes I have those **really sad conversations in my head**. And sometimes I have those **very angry conversations in my head**".*

> *"I **was very naïve** I would say about stuff like that. Just because I didn't come from a **family like that, that had a lot of problems involved.** You know, families all have problems, but for me it was kind of different to come into contact with families that didn't care for each other".*

Prior to intervention, one must arrive at the realization that mistreatment is actually occurring. Otherwise, without having answers to all of their questions regarding caregiver intent, the form of mistreatment, the necessity of the caregiver, the older adult's responsive behaviors and the demonstration of proof, practitioners could remain in that assessment phase or, unfortunately discharge that patient. Quite often however, those discharged cases lingered in their minds.

Some American researchers have studied the lack of action by some care practitioners, but all too often, the findings have pointed to a lack of knowledge about mistreatment or duty (Lachs et al., 1998; NRC, 2003; Ortmann et al., 2001). However, the findings from this study reveal different factors for a possible lack of action.

Once realization was reached, intervention planning began. Unfortunately, there were again more questions than answers. Practitioners described how most of their colleagues also did not know what to do. The American literature does speak to the complexity of these cases and how that can lead to uncertainty and possibly tolerating the mistreatment (Erlingsson et al., 2006; 2012; Saveman et al., 1993; Solomon, 2009).



Emotions.

The process of intervention was riddle with emotions: distress of wanting to protect the older adult or accepting that they could do nothing, the defeat, some feeling that they were alone in their efforts, or the distress that the older adult might be suffering behind closed doors. In the US, adult protective service workers do suffer from moral distress as they deal only with these types of cases (Bergeron, 1999; Dong, 2012; Killick & Taylor, 2009)

"Last week was particularly difficult. ***I want to take them hom****e (…) sometimes have to let them go…have to accept there is nothing I can do"*

*"****Well its defeating. Like, the police officer said, nothing gets done****. I have never had a case, a charge laid in any of these cases and I have been doing this for (#) years now".*

"I don't know, no (sigh). I think I am never ready for anything like that. I always feel, well what do I do? ***I never feel like I am ready for anything like this****. Even after all of these years in nursing. You know, I never feel ready for this".*

*"****Nobody is willing to step up****, and the people who are stepping up are quite concerned".*

"So, that's when you worry a little bit more, because they are more isolated and they don't have the support, don't have enough services to help them out. And ***things may be going on. And there are less people to be aware****".*

"There was no resolution to this even though we didn't know how to resolve this. The biggest concern that, the thing that ***I found most distressing for me was we couldn't, we had no access to solve those problems. Everybody else threw their arms up****".*

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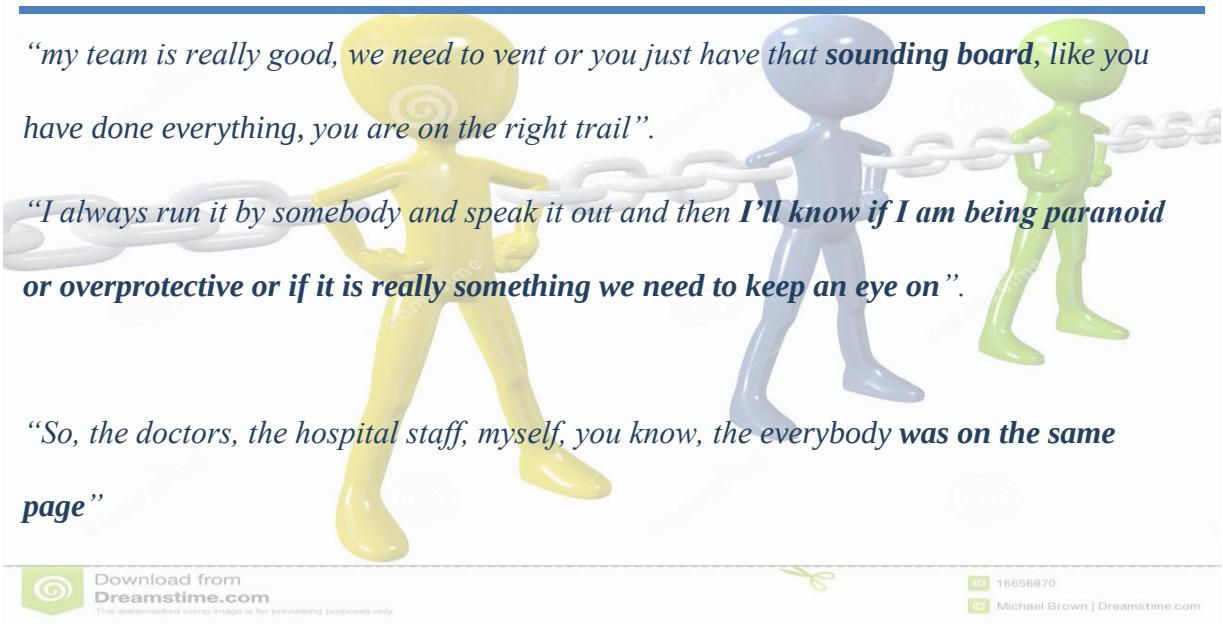
Strength of team.

Teams provided functions of debriefing, reassurance, unity and support. Most participants reported that team consultation and support were essential over the course of the case.



Community as team

This notion of team also needed to expand to community teams-whether these were formally instituted or occurring informally. The ability to « attack » the case as a team was deemed essential. Another interesting component of this notion of community, was not only the safety and well-being of the mistreated older adult, but that of his community, for example, having the resources in place especially in smaller northern towns. The last sentence touches upon a problematic aspect of the notion of team however where no one steps up and responsibility is actually diluted.

Control.

In their reflective journals, practitioners were asked whether they felt they had power to control outcomes of their cases. Most responses were a clear no and the next discussion on context will illustrate the factors that a professional cannot control. Generally, when the case was related to caregiver stress, most practitioners felt able to intervene to achieve positive outcomes.

3.3 Focus groups

The discussions held within these 5 focus groups were instrumental in gaining an understanding of not only the contexts within which practitioners must make decisions, but to appreciate viewpoints from 28 stakeholders, practitioners, practitioners, and volunteers representing 23 different community services and health care organizations. In hearing their perspectives, I developed an appreciation of the pressures experienced within the system and how these impacted the phenomenon of mistreatment of an older adult with dementia. It is essential to note that the members of these focus groups volunteer their time and efforts to the network within their community, some for numerous years.

Five two-hour long focus groups were conducted, transcribed, and analyzed using NVivo 11. The findings have been organized under the headings of legislative context, social context, home health and social services context, and professional practice.

"a parent can't abuse their child; a child should not be able to abuse their parents. And I don't think it's that complicated you know. We could figure it out to how to do it".

Legislative context.

In an ideal system, supporting factors would be embedded in public policy and law. An American social worker provides a vivid analogy: the law forms the skeleton of a program and policy provides the flesh to put that program into place (Mixson, 2010). However, such is not the case for OAM in Canada due to numerous gaps in legislation. Many participants described the current legislative system as being oppressive. Overwhelmingly, participants voiced disappointment with the lack of supportive legislation: "*there is no adult protective services act unless it's for the developmentally handicapped, physically or developmentally handicapped because there certainly are laws in that respect. But there are no protection laws in place or legislation much like there is Child Protection Services. You know so it's just a sort of a sense of well why isn't there?*"

This lack of supportive infrastructure for OAM was shared by many: *"…referring back to Child Protection Services, it's not simple, but the system is designed to provide protection and support from beginning to end and this one (OAM), this one isn't built that way. In fact, it's not built at all".*

"Two of our most at-risk sectors are our children and our seniors and we have legislation that protects children but we don't have legislation that protects our seniors. I think that would be a place to start".

"… compared to Children's Aid Society; they do have a legal counsel where for situations like that they are guided, they have supervisors, they have guidelines, we have none of that".

In discussing the need for at-risk sector police checks for practitioners working with older adults, one participant stated: *"Well if they're identified as an at-risk population why aren't they protected more? Why don't we have an agency to protect them?"*

Exasperation prevailed: *"it's the way the system is created, now if we were kicking a dog or a child, exactly, it's prescribed. You do this, you do that, you do that. But you kick an elderly person and she says, no I'm okay with being kicked, it's crazy, it's just so frustrating to work in this field. We've been dealing with this stuff for years and years".*

The complexity of the legislation was reported as a barrier in some cases: there is "*reluctance for some agencies to get involved because the legal aspect is quite significant as well" …* "*unless we somehow also tried to obtain legal guidance from a lawyer but who's to undertake that case on?".*

There is a continuum between the indicators of passive neglect of an older adult assessed by a professional in the community and the evidence required to demonstrate *"failure to provide necessities of life'* under the Criminal Code of Canada.

Criminal Code of Canada.

The Canadian public perceives that strong criminal laws may protect older adults from mistreatment (Ekos Research Associates Inc., 2011). However, many cases of OAM do not fit under the Criminal Code of Canada which does not specifically deal with elder abuse (Library of Parliament, December 3, 2012). One participant reflected on the lack of any charges of OAM being laid in her lengthy career with the police force, due to a difficulty in addressing it and the need for evidence. A continuum exists between what qualifies as criminal behavior and what is usually encountered in community that is not considered criminal activity (British Columbia Coalition to Eliminate Abuse of Seniors, 2006). Of great concern is the fact that OAM tends to worsen over time and, therefore, a case of passive neglect, if unaddressed, may progress and be fatal as demonstrated in case studies by Ortmann and colleagues (2001).

One participant explained that in terms of legislation, in essence it exists in the form of the Criminal Code of Canada but highlighted other important differences with legislation: firstly, legislation provides authority needed for police to apprehend a child for protection; secondly, in cases of domestic violence, powerful legislation obliges police to pursue charges whereas in OAM, a statement from the victim is required. Participants highlighted the challenge of such disclosure, especially with an older adult with dementia mistreated by their family caregiver: *"there would be a few times where she would forget where it (her money) all went. But then she would have moments of clarity where she knew exactly what had happened…that would be when she wanted to call the police. But then, usually by the time they got there, she would say he is still my son and I can't do that to my son".* Other important clarifications were offered in regards to police having no authority to breach the door of the home without reasonable suspicion that the person was in danger.

Participants overwhelmingly favored the development of adult protective legislation. In each focus group, discussion revolved around the appropriateness of developing OAM legislation inspired by child abuse or domestic abuse legislation, or the At-risk Adult Act.

In this study, participants shared many cases of abuse of power of attorney. The literature describes the abuse of power of attorneys encountered by practitioners and experts in this field as there is no mechanism in place to ensure continuing powers of attorney are used correctly (HRSDC, April, 2012). Challenges to the exercise of POA must take place through the courts which is costly, complex, & time-consuming (Law Commission of Ontario [LCO], 2012).

Adult Protective Legislation.

Participants yearned for the creation of positions similar to APS workers in the United States to whom they could report their concerns and who would take responsibility to manage the case: *"There has to be somebody that actually that that's their job". "Whose responsibility does it become? Who takes on the lead for such a case if there are a few services implicated with a client per se? It's very much a wide and very grey area where we don't know how to navigate, we don't know where to navigate to".* This need for support was highlighted in studies by Harbison and colleagues (2004; 2005), in rural Nova Scotia, one of the four Canadian provinces with Adult Protective legislation in which practitioners who must report suspected mistreatment to Adult Protection workers were interviewed. Practitioners described the importance of having these adult protection workers, even for consultation when not directly involved in the case. These workers were part of the interdisciplinary team, were trusted, assisted with brainstorm serving as a "sounding board" (p. 239), and assisted with crisis management. In the Ontario context, community practitioners must rely on each other, which these participants certainly did.

Participants in this study strongly stated that the lack of protective legislation is a reflection of societal ageism: *"I think to us (practitioners), we see them at risk, if I were to read this to someone on the street, they would probably see this as normal aging…. this is just part of Alzheimer's disease, this is how it works, this is what's to be expected. Weight loss, this is just how it works, so I wouldn't say most people outside of health care practitioners or police who see a situation like this would think this is a problem. If a child was not gaining weight appropriately, if a child didn't have food in the fridge, if a child was in a situation that would be a problem and I think it's pretty across the board consistent, everyone would say well there's a problem. This (OAM of a person with dementia), most people I would not say see it as a problem".*

"we have to change the way people look at it …. if there was a child who was abused nobody in society would stand for it, like people would be up in arms … But even some adult victims I think just kind of accept it themselves, and I think that starts with developing a changing mentality of society that it's not right and it's not part of becoming a senior

Some policy documents speak of empowering older adults to help them to navigate the punitive justice system (F/P/T Safety and Security for Seniors Working Group, 2007). However, this fails to recognize the deeply embedded familial trust relationship issue where it is unrealistic to contemplate empowerment of isolated at-risk older adults who are dependent on their abusers. Such statements also neglect the reality of OAM of a person with dementia, where although *"we tend not to want to intrude upon their civil rights…but we have to be* ***where*** *that person is (cognitively)".*

As an Appendix, I have joined my understanding of the pertinent legislation. I preface this by stating that although I have quoted experts in the field, I am not an expert in legislation and laws and therefore invite any feedback, corrections from Phase I participants. Clarifications/corrections will be brought to the Final report in Phase II.

Professional intervention.

Plan and risk.

Participants deplored not being able to offer a sound plan of action in these cases *"…because you can't give them any tangible outcomes you know. If someone is abusing their child you can anticipate a tangible outcome, it may be very complex and complicated but you can anticipate that. You can't with an older adult".*

"IF YOU TRY TO DO SOMETHING ABOUT IT, WHAT'S THE FALLOUT GOING TO BE? THERE ARE SO MANY SCENARIOS THAT YOU NEVER KNOW, YOU NEVER KNOW HOW IT'S GOING TO TURN OUT. SO YES, IT MAKES ME FEARFUL".

They also described a fear of increasing risk in a home as had been shared by others: "*because it could affect the mother…in a very bad way"* but yet having to *"ask those awful questions and (being) aware of the risk".* This fear was overwhelming for some: *"if you try to do something about it, what's the fallout going to be? There are so many scenarios that you never know, you never know how it's going to turn out. So yes, it makes me fearful*". Traditional caring roles of practitioners left them in uncomfortable situations when having to use the law: *"if we take the heavy hand and be the bad guy that relationship's compromised and that could have detrimental fallouts".*

In the absence of a legal avenue, participants remained focused on the aspect they could control, service provision. However, concern was expressed about possibly losing access to the home as practitioners proceeded carefully: "*we try to tiptoe around how to keep this person safe, how do I keep services in there so at least somebody is watching that nothing huge is happening…. really it's a matter of trying to watch carefully and not have things progress any further". "how you intervene and when you do intervene, our rapport is broken with the older adult because then they're not going to accept (our services) anymore and so it's very, very complicated… we can't get the doctor back in there, we can't get back in there"*. Some caregivers prevented access to the older adult covertly: *"often times they'll just prevent you in any way they can to get in the house… she's never alone, he's always there… and unplugging the phone….Exactly, and often times you're trying to set up an appointment, they call back stipulating that they have too much on their plate to take you on today and then it becomes you know postponed repeatedly and then it becomes another red flag to you, why aren't they accepting me in their home and then after a while it's okay, how long has this been going*"? A few studies have identified this notion of caregiver control over access to the home (Beaulieu & Leclerc, 2006; Fitzsimons et al., 2011; Omote, et al., 2007).

Capacity.

Most participants voiced frustration about dealing with the PGT and responses to their concerns. *"…a situation where an older adult is deemed to be at risk but basically the advice that you get at the other end, …is that well you know, here's a list of capacity assessors that you can hire".* These practitioners must take on these additional responsibilities but are these realistic expectations to make of a professional with existing heavy responsibilities and without this level of expertise? With children, a professional obligation is to inform suspicions of mistreatment to CAS. Here, there is no one to report to. Most discussions surrounding PGT were described overwhelming situations where the professional did not believe his/her concerns were validated. Consequently, the notion of consulting PGT has become omnipresent, and not a worthwhile endeavor, as echoed by one participant: "*next step is public guardian and trustee….and even that avenue it doesn't seem to go anywhere and we're back to Elder Abuse Ontario with help from them and then just yes, we're lost"*. This understanding could potentially act as a barrier to pursue cases. One participant described, from her previous position, a positive outcome from contacting the Advocacy Centre for the Elderly [ACE] to assist with a financial mistreatment case; the older adult was a resident in long-term care, and the mistreatment was from an outsider. In one focus group, hospital personnel and police reported a rapid response to their concerns, while community practitioners stated waiting for long periods.

"*next step is Public Guardian and Trustee….and even that avenue it doesn't seem to go anywhere and we're back to Elder Abuse Ontario with help from them and then just yes, we're lost*".

Formal capacity assessments were primarily viewed as a barrier to service planning because of the high cost associated especially in some rural communities who did not have this local expertise, the need for the older adult to accept the assessment, and convincing families to cover the cost: *"in itself might be creating a hindrance to accessing services".* On the other hand, capacity assessments were viewed as essential when a family member, with mal intent, was perhaps trying to obtain a POA from an older adult without capacity. Practitioners valued the ethical standards of those lawyers who *"asked all the right questions to see how cognitively affected he was"* as the opposite was also reported.

"we try to tiptoe around how to keep this person safe, how do I keep services in there so at least somebody is watching that nothing huge is happening.."

The hierarchy of decision-makers to be followed for POA prioritizes family relations which might be problematic when OAM occurs within the family. One participant describes the difficult position she has been in: *"They (OPGT) always try to defer to, they try every way possible not to get one on their caseload, try to defer to a family member and as service practitioners… you're practically begging someone in the family to provide this role for their family member and sometimes those individuals that are willing to pick it up maybe not be the best person for them but you're mandated to do that through that process, to try to find somebody to pick it up".* Components of past complex cases were presented revealing possible miscomprehensions of the PGT process and a potential avoidance of that process. As a helpful strategy, one participant recommended contacting ACE, based in Toronto. There were very few discussions of this resource in focus group discussions.

Persistence despite legislation.

Interestingly, some spoke, not of a duty to report, but of a duty to protect: *"care practitioners, physicians, nurses, anybody that is in that circle of care for that person, it is their obligation to protect".* Participants describe not giving up: *"it's insidious so you know when it comes out we would like to think that we have the response and we can fix it but even the government doesn't know how to fix it so we're always at a bit of a loss but never just throwing up our hands and saying we can't do anything about it".* Persistence was viewed as the only way to progress forward: *"if you ask a child you know, can I take you away from your parents they're likely going to say no, they don't have a choice because we're acting in good faith for. I think that we need to systemically move a little bit more to that end where, if in my professional opinion, this person has some type of cognitive impairment, and is not able to make informed decisions, then we'll go in and as a professional, I will ethically and do my due diligence to protect this person, like we would children or animals".*

"It's an anomaly, this particular field of seniors at risk and elder abuse … I don't know that it is on anyone's mandate at this time,

Social context.

Historical.

Some participants, with many years of experience in their field, expressed frustration about the lack of progress in this field as well as the lack of responsibility for this phenomenon: *"It's an anomaly, this particular field of seniors at risk and elder abuse … I don't know that it is on anyone's mandate at this time, clearly identified as being a component of an organizational mandate to address elder abuse".* As a result, cases are *"picked up in fragments".*

Dismay was also expressed regarding losses of community supports such as a previously paid position through New Horizons funding for a network, grant monies for community projects, and the replacement of Seniors Issues Officer positions with community safety officer positions. These losses are perceived as symbolic of the importance attributed to this phenomenon: "*it indicates a lack of interest in the senior's issues as well you know, and as a society".* Practitioners were passionate about bringing some resolution to OAM and expressed solitude in this fight; a fight that they take on voluntarily, in addition to their regular employment obligations. These losses felt like *"a slap in the face...devastating".* One community had annualized funding and with that, were able to deal with cases: *"we got things done…. dealt with*

cases, we were soaring". Those losses have been very discouraging and the unsuccessful struggle to obtain grants has some concerned that they could *"easily fall apart".*

Another change, for those with many years in the field, was the ability to share concerns about cases with other practitioners in the case prior to PHIPA. The introduction of privacy regulation contributed to the creation of professional silos: "*people started to be very protective of their information, confidentiality, liabilities*". However, some experts explain that PHIPA actually broadened the ability to report abuse (Solomon, 2009-see Appendix A).

Some small communities described additional threats to the well-being of their communities. They described insufficient community resources to help their aging population to age in place, the presence of "*vultures*" in the community, strangers attracted to the aging community and befriending isolated older adults, the lack of informal family supports due to outmigration of children, or unemployment of adult children remaining. Also, adult children sometimes moved back in with their parents, often times without malice, but unfortunately sometimes for opportunistic reasons resulting in mistreatment.

The consideration of mistreatment as a societal issue is crucial to exposing it. Otherwise, given the importance of the institution of family, the context of the domestic setting often remains invisible and

Strength of community focus.

Although concern over OAM does not yet derive from widespread Canadian societal concern (Harbison et al., 2012)., over the course of this study, I met with very community-minded practitioners who verbalized the importance of viewing this as a community problem, to be addressed with a community response, to better support practitioners; "*bringing that collaborative approach to those societal or social issues and elder abuse is predominantly a social issue correct?"* This consideration of mistreatment as a societal issue is crucial to exposing it. Otherwise, given the importance of the institution of family, the context of the domestic setting often remains invisible and OAM remains relegated to a family problem rather than a societal one (Brandl & Raymond, 2012).

In all five focus groups, community well-being was always the focus: *"we are representative of the community that works with seniors at risk in the home, personally, professionally, just trying to make sure that we remain informed and that there is a network that we can rely on even just for identifying issues and what we can do about them".* Networks described hosting numerous awareness building events in their community about OAM.

Participants also looked forward to the development of the dementia strategy to educate their community so as to raise the consideration and respect for people with dementia: *"What do we do when somebody has dementia that wants to be part of the community, live in the community, and yet they don't have that ability anymore to realize? How can we educate the community? She needs to belong to the community".* This community education might also reduce the normalization described by an earlier participant (p. 27).

Societal family expectations.

When asked, 94% of Canadians thought that family played the most important role in protecting older adults (Human Resources and Social Development Canada, 2008). This highlights the societal paradox whereby society would have difficulty coming to the realization that children are the most likely perpetrators of mistreatment (Choi & Mayer, 2000; Lachs et al., 1998; NRC, 2003).

> *"it's presented to the son and the daughter in the way of we're here to help as opposed to what are you doing that's making her scream?"*

A primary tenet of our society is that families should provide care to their parents. Professional perception is that long term supportive care, such as caregiving for a loved one with dementia, is a family responsibility versus that of the home care institution (Hollander, Chappell, Prince, & Shapiro, 2007). This assumption of family caregiver responsibility was expressed during the focus groups: *"I mean that's her mother, she needs to follow-up. She has to realize the responsibility of being a POA"; "What happened to families taking care of families? When did that stop? I don't understand like where's the responsibility of families in this".*

However, there was also an uneasy understanding that families may not share this perception: *"that daughter would have to get involved because she is power of attorney…. That's an expectation (of family), it's not a reality".* One participant regularly reviewed POA obligations with caregivers including an available 8-page handout listing obligations, process, and helping them organize receipts. She reported this underlined the importance of their obligations and demonstrated external oversight.

Many participants expressed disappointment with low societal expectations of an adult child mistreating a parent *"that's how the rest of society sees him…people can see him as being owed something, having sacrificed himself for moving into the home, so people can see that as well, he deserves to get something, some kind of compensation when really he's taking advantage of a at-risk individual".* Such societal perceptions were perceived as contributing to mistreatment.

Caregiver stress: A risk factor.

Caregiver stress, as a risk factor for OAM is not recognized in the literature as a certain causative risk factor (Buckwalter et al., 1996; Chokkanathan, 2014; Kosberg, 1988). However, many practitioners in this study disagreed. They were adamant that formal services in the current health care system are insufficient to support caregivers in their enormous role with a person with dementia: *"…not having enough support, and people truly not understanding what it's like to live a 36-hour day, nobody understands that right?"*

It is interesting to note that, in Ontario, some strong advocates for autonomy, opposed to adult protective legislation, propose that the ideal response to OAM is to provide supports and services to older adults to "avoid becoming dependent on their family caregivers" (LCO, 2012, p. 104). This, of course, is not realistic with older adults with dementia as the family caregiver is essential to their plan of care to remain in the home.

In keeping with caregiver stress as a risk factor, some practitioners suggested family meetings to show support *"we arrange a family meeting to give support to the family but also consider them innocent until proven guilty, we can try and educate them, try to give them some support as well but try and find out what truly is in the best interest going forward".* The approach of the

professional was key: *"it's presented to the son and the daughter in the way of we're here to help as opposed to what are you doing that's making her scream?"*

Home health care and social services context.

Lack of safety in the home context.

OAM occurring within the home context presents an additional layer of complexity in that safety cannot be ensured within that context: *"especially when it's a family member that's doing the harm right. I feel it's just that much more difficult to get to help them".*

Hospital admission, a few retirement safety beds, long term care respite or admission were the only options available. A new initiative called *Assess and restore collaborative*, was mentioned as a possible strategy to place a mistreated older adult in hospital for a two-week period for physical assessment, thus providing some time for investigation out of the home. Once in hospital, interprofessional case management and capacity assessment covered by OHIP could be achieved. *"When a patient, if a person like this was to be admitted to hospital then you know it becomes a case where all of the associated and involved parties you know address what can be done".* Unfortunately, older adults came to hospital in crisis: "*so if they're living in the community …if we have people who we are concerned , …very often, at the end of the day, we just have to wait, we have to wait it out"… "Wait for the crisis, … we see a great deal".* Shelters for women were discussed but were not deemed appropriate for a person with dementia.

In one community, a Rapid Mobilization Table was offered as a possible strategy to mobilize services to work together on a case. OAM cases could potentially be presented to the committee, *"but the person has to be in crisis".*

Caregiver support services.

Exasperation was voiced regarding the lack of support for caregivers in the present health care system: *"it's almost like there's a sense of apathy in spite of all the reports that have come out, and you know what's coming, we know that tsunami's already here, it's not coming, it's here! That we haven't, like the system just doesn't recognize the need to focus on how to better provide care and support to caregivers".* Canadian policy documents have issued this warning for many years now. Since the Romanow report (2002), experts have been projecting the need to strengthen home care based on the growing older adult population. More recently, the need to reform the home care system has highlighted (Brasset-Latulipe, Verma, Mulvale, & Barclay, 2011; Drummond, 2012).

Despite all of these policy documents, participants expressed that the systemic issues were "*still the same*". Participants expressed empathy for caregivers of older adults with dementia: "*there's a limited number of*

"because we had already brought this up a year and a half prior that we had concerns but we just kind of wait for the ball to drop unfortunately with a lot of these cases, we're waiting for you know something severe to happen or them to go into hospital or crisis and

hours that caregivers are allowed to have of respite in the home. They need more. I'm sensing so much burnout from caregivers and then we want to prevent abuse so that's prevented by supporting the caregivers". Limited respite hours prevented caregivers from attending support groups as caregivers *"they have no one to take care of the person at home (who requires supervision)".* Participants were hesitant to even use the term mistreatment in discussing these cases, thus reflecting their empathetic understanding of these challenging caregiving situations.

Service allotment and risk.

Many felt that the level of care provided via in-home supports was insufficient with high-risk clients. Administrative practitioners expressed irritation with insufficient funding resulting in an inability to provide the services and hours allotments indicated in Ministry of Health policy: *"even though on paper it looks beautiful, when it comes down to actually providing the service and working within the parameters that you have available to you, which is the almighty dollar unfortunately, you just can't provide that 5.5 hours or even all of the things perhaps that are listed in the policy that would be part of the program, so that's frustrating".*

"you have to rely on a regional agency to help you out with something else, well good luck. How can you make this case go forth and how can you go about providing care to somebody when you have to rely on an agency that's in (an urban hub)? And you're three hours away or on the coast where you don't have access to them unless you travel by train, … it's part of our reality".

Geographical: Northern/Rural.

A prevailing ideology is that rural informal networks can compensate for the lack of formal services. A participant described the strength of her rural community: *"it's a strength in terms of the neighbours and care practitioners looking out for one another. Everyone knows everyone".* In focus groups, Cornes and colleagues (2010) discovered that some rural communities were able to mitigate risk, but this was less possible in more remote and isolated settings. In this study, findings varied in the different communities. Volunteers certainly played an important role in some small communities: "*We would like to see more but we have a fairly good group of volunteers, (helping) several clients who have the diagnosis of Alzheimer's, provide support for the family while the individual is living at home*". However, there were many more challenges identified at the formal services level.

Participants described inequities concerning access to services and options in northern and rural regions. This has previously been identified in the literature for older mistreated adults in rural and northern communities (Human Resources and Skills Development Canada [HRSDC], 2012). In the focus groups discussions, a case scenario, created by myself and my colleague, both from an urban centre, was presented to the teams. It was interesting that in all rural areas and some northern urban hubs, the formal care provided in the scenario was described as being "*unrealistic"* as many of the services were simply not available. Long wait lists for high-risk senior programs and for crisis long-term placement were described: *"…making a referral is sometimes just a stop-gag…wait lists, you know you're connected now but you're not really connected and they still struggle and they still wait and they end up at hospital because it hasn't occurred you know". "I see a lot, and three months later, the damage is done".*

Some considered specialized services of dementia care to be localized in the urban or "*have communities".* Disapproval was voiced that services are not standardized throughout the

province. Day programs did not exist in some rural areas where families would have to drive 1.5 hours to access a program. This was especially problematic when travelling winter roads.

Some rural practitioners felt quite isolated*: "you have to rely on a regional agency to help you out with something else, well good luck. How can you make this case go forth and how can you go about providing care to somebody when you have to rely on an agency that's in (an urban hub)? And you're three hours away or on the coast where you don't have access to them unless you travel by train, … it's part of our reality. Who do you turn to? It becomes very disconnected…there is nothing tangible, there is nothing, you feel at a loss kind of thing yourself, and you want the best for that person you are trying to help, you're trying to offer them support and reassurance and all that and you can't".* In northern hub centers, in home service concerns were noted for their outlying rural areas, not within the city. Influencing factors were travel time and a limited pool of resources.

Recruitment and retention was problematic: positions remaining vacant for lengthy periods of time for both professional positions as well as personal support workers. Many programs were provided via satellite offices leaving their practitioners unsupported at times: *"with satellite offices your supports are away and sometimes you can't necessarily get them when you need them"*. In some areas, satellite offices were not existent, practitioners worked from their homes, a situation which did not permit them to properly service their community. Lacking expertise in their community lead to existing practitioners having to expand the scope of their practice: "*with satellite offices you have to be Jill-of-all-trades because there's nobody else"*. When expertise did exist, communities considered this a "*privilege".*

> *"…afterwards it's up to you to try to figure out resources, who you could try to call to figure out who's going to help you out with this and how can you address this… we're left to deal with these things on our own*

In other regions, practitioners working in some of the northern hubs with their surrounding rural areas worked tightly as a team. "E*verybody is a resource and it's a matter of getting together and brainstorming and trying to do your best…because we are in the rural area and there are very limited resources, I think we are all becoming resources, and if every door is the right door, I think that is where we can have the strength"*.

Professional practice.

Knowledge.

Frequently in the literature, practitioners are reported to lack knowledge of OAM. This study revealed quite the opposite: learning from these groups was a humbling experience. Participants were keenly aware of risk factors, indicators, and the presentation of mistreatment. In cases of dementia, practitioners were cognizant of having to investigate further as the older adult could not necessarily declare the mistreatment: *"There's something not right and you pick up on that and you might be wrong though so it needs to be fully investigated".* Most were adamant to investigate the mistreatment, identify its etiology, and wanted to intervene to put an end to it. It is at this point that the plan of care unraveled: *"what do we do with this? Where do we go that we know there's going to be a solution and a plan in place"?*

Interestingly, multiple exposures to mistreatment did not result in having the answers but rather exposed more questions and uncertainty. Instead, participants voiced frustration with the system that wasn't progressing towards intervention: "*Provincially and federally we have been very proactive in identifying and educating seniors as to what abuse is, the types and everything else but then what do we do afterwards? Where do we turn to? Those are not identifiable, other than trying to determine, am I right to think that this is a legal issue? and then it's not all that much of a legal issue because they don't have venues or laws to protect them".* In addition, some felt very alone in their fight*: "we've been proactive with informing people of what is abuse, what it might look like, what it might imply but afterwards it's up to you to try to figure out resources, who you could try to call to figure out who's going to help you out with this and how can you address this… we're left to deal with these things on our own and it's shameful".*

Guidance.

Under the *Home Care and Community Services Act, 1994*, there are two fundamental expectations of community agencies approved to provide in-home care. Firstly, the agency must develop and implement a plan to prevent, identify and manage OAM. Secondly, the plan must ensure training of that agency's employees and volunteers (Ministry of Attorney General, 2011a).

Most participants were not aware of any guiding policies and procedures from their organization regarding OAM. Those involved in networks were quite aware of this limitation: *"You know how many people that sit on our committee have their terms of references or their organizational mandates include language around elder abuse? None, probably none or very, very few which is sad".* On a positive note, most practitioners stated they would advise their supervisors of any mistreatment situation as a first step and were sure they would be supported. Practitioners wanted education from their employers and voiced disapproval of the lack of frequency of such training: *"but it's like, do you have education on elder abuse? And you did that one in-service three years ago, check*". Practitioners spoke of high turnover and the need to repeat training.

Supportive networks.

Working in teams was the primary strategy identified in this study. One participant's comments illustrated this importance: *"it takes a community to prevent elder abuse … people need to support one another and to be aware of speaking out …we have a lot of partners that are on board … one step at a time, baby steps sometimes in this situation, it's one way of being able to address a major issue".*

Some participants described informally created teams of trusted colleagues sharing information under the principle of the Circle of care, providing consent had been obtained to share with the other organizations: "…*there is a confidence in the people in the community that can assist, formal and informal….we need to network and brainstorm in just about every situation … there is a sense that again we can't guarantee the outcome that we want but at least there's an opportunity … the people that I work with in all of the agencies and services, whether they be local or outreach or regional, all have that sense of commitment and investment in trying to do what needs to be done".*

Primary care practitioners, either physicians, nurse practitioners, and family health teams, were instrumental in providing support and sometimes the lead in these cases. This role was pivotal in some cases where evidence was required for further police involvement. Without that primary care practitioner, frequent emergency room visits might result. In one area, the primary care physician validated in-home practitioners' concerns and assisted in the case: "*primary care practitioners are a huge piece to the puzzle because often if I'm concerned about a case I will call or if our Care of the Elderly (physician) sees a patient, and we're telling her we're having*

that gut feeling something's going on, they're not letting us into the house, she can Form the patient and get them sent to hospital and we can evaluate a little bit further about what's going on".

Established Elder Abuse Ontario networks were also viewed as providing support and education, some providing case consultation. Practitioners sought support from them: "*I think that there's a confidence around the fact that the network is there. There's a confidence around being able to call someone to just consult, just to debrief, just to throw it out there and say I don't know what my next step should be, and just to be able to talk it out";* "*networks where practitioners can come together and discuss and look at solutions or look at pathways to create safety for seniors, …they're empowering so that as practitioners (can call and say) Can you help me?"*

Discouragement.

There was a sense of dismay with the lack of progress in the system: "*here we are years later in the same situation we were back then…and more and more are being faced with the same issues…Exactly but nobody feels that there is any use telling anybody because nothing gets done". "it is discouraging for us as a group to sit at round tables, always come up with the same issues and never a resolution and never action"*. When presented with a fictional case scenario, comments revealed the common nature of these cases: *"It's unfortunate but we see this more than this case study isn't a shock to anybody around this table… and that's the sad part".*

Many participants expressed exasperation with the limited involvement of some organizations who were not involved in discussions and did not participate in meetings. Some assumptions of lack of interest were shared, while others speculated that their heavy workload did not permit their participation: "*we need to have more agencies around the table. (Name of organization), they're not here because they don't feel that they can take the time out".* Others offered that their absence might be related to the lack of progress in the field: *"if you think about it, unless there's something productive coming out of a three-hour meeting, like unless we can go somewhere…".*

Lack of professional agency.

Participants voiced an inability to intervene to resolve situations of mistreatment and actually sometimes felt that they were part of the systemic problem versus the solution: *"I tried that too, I can't get anything done… so how am I helping him? I'm not helping him, I'm just another wall".* Some community networks concentrated on functions of educating the community versus offering a case review process. A realization of how little control they have over the outcome of cases given the absence of legislative support and infrastructure has led some networks to no longer offer case review as they cannot offer solutions. Some offered their emotions related to working in this field*:*

Organizational demands.

Participants described service limits and eligibility criteria that sometimes prevented practitioners from intervening as they felt was needed. Appreciation was given for those practitioners who were creative: *"in spite of the rhetoric and the ground rules, you know they don't break them but they become very creative in terms of how to get people services"*. On the other hand, some critiqued new policies that had to be followed, unfortunately sometimes targeting that professional. Within the circle of care, it was felt that practitioners from some agencies did not pursue cases far enough: *"how often do we hear that from the (name of profession) saying, it's not our mandate, our services are voluntary, you know if they slam the door in our face we can't go…and they will then say, they are refusing services".* This was considered not meeting professional obligations: *"that's a systemic issue that needs to come from*

higher up to recognize that the at-risk seniors and adults in our population, that there needs to be a mechanism for those (practitioners) that want to do their jobs".

During focus groups, it was revealing to have some participants share their limitations, the legislation they had to follow, and to witness the resulting new level of understanding and common ground reached by the team. These were challenging discussions to have however due to conflicts from past difficult cases. Sharing of roles, responsibilities, limitations, language, and legislation was a productive endeavor for these groups.

Lateral conflict.

All practitioners voiced exasperation in the gap between the legal system and the health care/social services system which appeared to be at odds with each other. However, practitioners have no choice but to function within the present legal system which dictates specific legislation. Practitioners voiced hopelessness in a "*broken system*" that did not support their efforts to eradicate the mistreatment. It was felt that some practitioners *"normalized"* some cases, in part due to the frequency of cases, in part due to the filter of responsive behaviors with dementia that may prevent them to see the mistreatment: *"it's the behaviour of the patient that's looked at in a lot of cases and that abuse is sometimes overlooked".*

Practitioners, who are socialized within their respective disciplines, might hold assumptions or expectations about their colleagues that are possibly not realistic. An underlying obstacle to their collaboration is a misunderstanding of each other's limitations attached to their roles. For example, within one focus group, two members had the following exchange about how far to proceed with a mistreating caregiver declining home services:

-"Well that ends my job right there, I can't do anything, can't force you. I can't force you to (accept services for the patient with dementia where mistreatment is suspected).

-I know but it wouldn't trigger any alarms like for you as?

-Oh for sure, no, no.

-Okay but you would take it one step further?

-Yes, but I can't, you can't force your way in in anybody's house.

-No, no, no.

-If he doesn't want anybody.

-Yes, I guess I'm just hoping that you know as a professional…. That you would say okay, whoa, something's wrong here and you know like…."

"Deeply saddened doesn't even cover it, mainly because I know at the end of the day there's not a whole lot more I can do for them …I don't even know how to describe it, … it's just a reality"

… "we cannot as a system, as an evolved society we have not yet figured out a way to protect the elderly. That you know, it makes me so angry".

What are the expectations of practitioners? As demonstrated throughout this analysis, there is no clear answer to this question. Legislation, society, professional regulatory bodies, nor colleagues cannot provide that answer for practitioners. All of the participants in this study wanted to help the older adults and caregivers in their care but most could not find the guidance within the present context to do so. One participant expresses her discouragement of being unable to resolve the situation and being unsatisfied with the outcome: *"we're all hung in the air with information and we don't know where to go with it. As well, either it's going to end up being nothing that we're impressed with, or that we say, oh call this number and then you know this is going to get solved for you, it's not. There's nothing". "you would hope that in the years of dealing with this type of situation that there would be a road map for practitioners and clearly there isn't you know? Because we're all sort of dancing around what are we doing for them"*

Following analysis of these focus group discussions, and in reviewing the lack of support on numerous levels for these practitioners, it became apparent that a common sense of group agency is required and it is hoped that Phase II can contribute to that collaborative effort. All of these practitioners are guided by the desire to correct a wrong, to advocate for those who cannot do so for themselves, to protect, ensure well-being, and care for the older adults and caregivers in their communities. This level of personal investment was evident in interactions with all of these participants and is well reflected in the words of one participant:

Conclusion

Professional voices

The literature is replete with statements that practitioners "ought to, should, and must" intervene in cases of mistreatment. However, the voices of health practitioners involved in complex cases of mistreatment are seldom heard.

"I have given a lot of thought to my role, and many times wanted to resign because I felt that we have not progressed enough in the last 20 years. However, upon reflection, I know that I could not turn my back on this issue… As I am putting these feelings on paper I know that someone out there is being neglected and abused and we are not doing enough to help them".

This study is providing a voice for rural and urban practitioners in Northeastern Ontario to share their challenges and

successes with OAM and dementia in the home care context. The analysis of these findings aims to describe how the context within which they are embedded influences agency. By permitting practice to inform research, the field of OAM might gain much needed knowledge.

Next steps

The primary goal of Phase II is to act to improve that professional agency (Fontana, 2004). In discussing empowerment, Chavasse (1992) stated that practitioners "cannot empower others...until they are empowered themselves" (p. 532).

> *The aim is to develop a "critical mass of visible solidarity….to enact social and political change"*
>
> Kamberelis & Dimitriadis, 2011, p. 552

Therefore, participants from Phase I are now invited to come together for education and action. The estimated size of the groups will be of 9 participants. This method will be able to replicate the dynamics of everyday life social interactions for these practitioners who, ideally, would come together to manage cases of OAM (Kamberelis & Dimitriadis, 2011). The goal is to achieve richer, more complex and collaborative understanding (Choudhry et al., 2002).

In the literature, action outcomes resulting from applying a critical social theory lens might take the shape of community sharing of research results, workshops or academic presentations offered by participants (Choudhry et al., 2002); critical thinking and problem solving skills (Blake, 2005); moving from passive to active thinking (Lyons, 1999); creating recommendations for undergraduate curricula (de la Rue, 2003); empowerment (Stockwell-Smith et al., 2010); and consciousness-raising activities, lobbying government agencies (Kamberelis & Dimitriadis, 2011). In this last phase, it is hoped that the focus groups of champions will have the power to "reinforce a common sense of agency" (Mkandawire-Valhmu & Stevens, 2010).

Practitioners "cannot empower others…until they are empowered themselves"

(Chavasse, 1992, p. 532)

Ideas for action projects from Phase I

As you read the report, feel free to jot down projects ideas that would be of interest to you in Phase II. More homework…

Existing Pertinent Legislation

"Under the current regime, any person, including health care practitioners, *may* report suspected cases of abuse or neglect; however, reporting is not mandated except where the older adult is a resident of a Long-Term Care Home (LTCH) or a tenant in a retirement home. In addition, health care practitioners must report any suspected sexual abuse by another health care practitioner, no matter the setting. Should any person suspect abuse of an older adult, they may contact the police if the senior is capable, and either the police or the Office of the Public Guardian and Trustee (OPGT), if the senior is, or is suspected of being, incapable" (Advocacy Centre for the Elderly, [ACE], 2016, p. 5-6).

Under the current regime, if an adult with mental capacity gives consent to share information with another person or agency, there is no violation of privacy rights. When capacity is lacking, the health professional must consider criminal laws, capacity, substitute decision law, privacy, professional regulatory bodies, and the context within which the mistreatment is occurring.

Listed are existing pertinent legislation:

1. *Criminal Code of Canada*- there are many forms of elder abuse that constitute crimes under the *Criminal Code*. "These include assault, assault with a weapon or causing bodily harm, sexual assault, forcible confinement, breach of duty to provide necessaries of life, uttering threats, intimidation, theft, theft by a person holding a power of attorney, fraud, extortion, stopping mail with intent or forgery. These crimes can be reported to the police but a police report is not mandatory" (ACE, 2016, p. 11-12).

2. *Substitute Decisions Act of 1992*- a healthcare practitioner who believes that a substitute decision-maker did not act in accordance with the person's expressed wishes or in the incapable person's best interests can apply to the Consent and Capacity Board (Wahl, 2012). "The Office of the Public Guardian and Trustee [OPGT] has a duty to investigate any such allegations, but again, the law stipulates that the person must be at the risk of suffering serious illness or injury, or a deprivation of liberty or personal security" (Wahl, 2012). The healthcare practitioner must provide evidence that the victim is incapable of managing his property or personal care; evidence that serious adverse effects are occurring or may occur as a result. To disclose without consent, "the custodian must believe on reasonable grounds that the disclosure is necessary for the purpose of eliminating or reducing a significant risk of serious bodily harm to a person" (Wahl, 2012).

3. The *Personal Health Information Protection Act of 2004 [PHIPA],* can be helpful in that it gives health information custodians (HICs) broader power to use and disclose a patient's personal health information (PHI) without consent. Therefore, PHIPA actually broadens the ability to report abuse (Solomon, 2009). Specifically, "Disclosure without patient consent, specifically in regards to OAM, can be done: To eliminate or reduce a significant risk of serious bodily harm to a person (s. 40(1)); To the Public Guardian and Trustee (s.43(1)(e)); To a person carrying out an inspection or investigation under a warrant, or provincial or federal law" (s.43(1)(g)) (Canadian Centre for Elder Law, 2011).

4. The *Regulated Health Professions Act* (s. 36(1)(i)) "permits disclosure without consent for reasons that parallel the exceptions under personal information legislation, including to aid a police investigation, where required by another law, or: If there are reasonable grounds to believe that the disclosure is necessary for the purpose of eliminating or reducing a significant risk of serious bodily harm to a person or group of persons" (Canadian Centre for Elder Law, 2011).

5. Context: There is currently no law in Ontario enforcing the mandatory reporting of mistreatment other than the following acts: *Child and Family Services Act, Long Term Care Homes Act, Retirement Homes Act, Coroner's Act, Highway Traffic Act, Regulated Professions Act* (Solomon, 2009; Wahl, 2012).

   Current proposal 2015-16
   A private member's bill seeking to amend the *Substitute Decisions Act*, [SDA], 1992) and the *Regulated Health Professions* Act, 1991 [RHPA] passed second reading by the Legislative Assembly of Ontario on December 10, 2015, and was referred to the Standing Committee on Social Policy.

   Bill 148, the *Protection of At-risk Seniors in the Community Act, 2015*, was introduced by member Soo Wong, of Scarborough–Agincourt (Legislative Assembly of Ontario, 2015). It seeks to amend the SDA to make it a requirement for regulated health practitioners to report any reasonable suspicion that a senior is being abused or neglected. Also, the Regulated Health Professions Act, 1991 is amended to make it an act of professional misconduct for a regulated health professional to fail to report a reasonable suspicion that a senior is being abused or neglected as required by the Substitute Decisions Act, 1992. Practitioners would include, but not be limited to, doctors, nurses, dentists, physiotherapists and chiropractors, occupational therapists, and pharmacists, who would be required to report the suspected abuse to a law enforcement officer, the Public Guardian and Trustee, or another prescribed person. The Bill enforces the obligation to report by making it an act of professional misconduct for any health professional to fail to do so. At the same time, the Bill provides protection against such practitioners who report, by stipulating that no proceeding may be commenced against a health professional for making a report, provided it is made in good faith.

The response from ACE to Bill 148, dated February 22, 2016, can be viewed by following the link in the references.

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Appendix M- Consent Form for Focus Groups-Action

Dear participant,

You are being asked to participate in a study concerning the professional practice involved in cases of mistreatment of older adults with dementia by a family caregiver. I am interested in learning more about how practitioners, such as yourself, manage cases where older adults with dementia are mistreated by their caregivers in the home. In a larger sense, I want to learn about the forces that come into play influencing your everyday management of these cases. Lastly, I am interested in your challenges as you encounter and contemplate these types of cases, decide upon your interventions, and act in a way that is meaningful to you. This study is conducted within a PhD thesis.

Your participation entails participating in an action focus group lasting approximately three hours. This focus group will be audiotaped and transcribed verbatim. The regional consultant will co-facilitate the focus group discussions. Travel costs to a central location for the group, at a rate of 55¢/km, will be reimbursed and a lunch provided. Funds have been obtained to rent a meeting room for focus groups as needed.

Participation in this research project is completely voluntary. You have the right to decline to participate. You may change your mind at any time and withdraw. You may choose not to answer questions or to stop participating at any time. Whether you choose to participate or not be disclosed to your employer or supervisor.

All interview data and demographic information collected will be assigned a code number. Your name and the name of your organization will not appear on any information collected except on the research consent form. The shared information will be summarized along with information obtained from other participants. When the results of this study are published or presented at a research conference, your name and any identifying information will not be used. All individual information will be kept confidential and will not be accessible to persons not connected with the research study.

Transcripts and audio recording will be password protected and stored in a locked filing cabinet in the researcher's locked office, located in the School of Nursing, Laurentian University. Consents will be stored separately using the same precautions. All audio data will be destroyed by recycling once findings are published. All paper records will be shredded then cross shredded after completion of the study.
For focus groups, confidentiality cannot be guaranteed if participants choose to speak outside the context of the research. The importance of maintaining confidentiality will be discussed at the beginning and conclusion of each group session.

The sharing of these experiences during the interviews may have a therapeutic effect for you. Although as a professional, you may encounter such cases in your everyday work life, sharing of the challenges in this practice might elicit distress. I will conclude each focus group by reviewing with you the contact information of the employee assistance program of your organization.

Prior to any data collection, the legal considerations of sharing information regarding OAM must be reviewed. In Ontario, there is no legal responsibility to report OAM as there is no adult protective legislation. However, if, during the course of the interview, you share that an older

adult or caregiver is at significant risk of serious bodily harm … violence, suicide, imminent danger, I will review existing pertinent legislation with you. (Canadian Centre for Elder Law, 2011).

As an acknowledgment, you will receive a USB key with resources pertaining to OAM and dementia and outcomes of the action phase of the study. Hard copy interim and final reports will also be produced and disseminated to all participants to share with your organization.

If you have concerns or questions about this study, you may contact me, the student researcher Jeannette Lindenbach, from Laurentian University, Sudbury, at 705-675-1151 or toll free at 1-800-461-4030, extension 3824 or at jm_lindenbach@laurentian.ca. You may also reach my thesis supervisor, Dr. Kristen Jacklin, at 705-662-7277 or toll free at 1-800-461-8777, or at kjacklin@nosm.ca

If you have questions or concerns about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact a Research Ethics Officer, Laurentian University Research Office at 705-675-1151, ext 3681 or toll free at 1-800-461-4030 or email ethics@laurentian.ca

(For NE SGC consent, add: Your Rights as a Research Subject: If you have any questions regarding your rights as a research participant, you may contact the Health Sciences North Research Ethics Board at 705-523-7100, ext. 2409 or by email: reb@hsnsudbury.ca. The Research Ethics Board is a group of people who oversee the ethical conduct of research studies. These people are not part of the study team. Everything that you discuss will be kept confidential.)

Your signature below means that you voluntarily agree to participate in this research study.

_____	_____
Participant signature	Date
_____	_____
Researcher signature	Date

Appendix N- Focus Group-Action Guide

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1. During Phase I and II data collection, the following changes were noted as needed to empower practitioners in these cases. (list them-Pedagogy component) Without thinking of the feasibility of these, can you collectively brain storm the benefits of these?

2. I'm going to ask you to think outside the box now; therefore, not reflecting your currently reality, but where practitioners were empowered to intervene in a meaningful way. What would that look like?
   Prompt: absence of ageism
   Crime/mandatory reporting
   caregiving formally recognized
   mandatory reporting
   consultation team
   changes to home care
   support from your organization
   training for practitioners/community
   Community Response Networks

3. Which change would you like to collectively take on as a group?

4. As we are considering changing the present status, not a small goal, lets start small and break down this goal into sub-objectives. Can we begin with one sub-objective, one piece of this project.

5. Continue sub-objectives until goal broken down into SMART objectives. Guide team to establish working plan.

Appendix O-Final Report

Connecting stakeholders in Northeastern Ontario to collaboratively act on barriers and opportunities to address OAM in cases of dementia:
A two-phase study

Final Report: Phase II

The Action Phase

June 2017

Prepared for study Participants

By

Jeannette Lindenbach

PhD candidate

Laurentian University

Connecting stakeholders in Northeastern Ontario to collaboratively act on barriers and opportunities to address OAM in cases of dementia: A two phase study

Final Report: Phase II

The Action Phase

Acknowledgments

This Final report, with findings from Phase II of the study, presents the rich contributions of 31 Northeastern Ontario practitioners who strive to put an end to the mistreatment of older adults and ensure that those with dementia receive quality care from the formal and informal support systems. Faced with the findings of Phase I, participants were challenged to imagine actions, like pieces of a puzzle, that could serve to improve their present contexts. Participation in these focus groups was difficult and participants demonstrated that they are not willing to give up in their vision for a future where the Ontario socio-legal and health care contexts will support them in their efforts. This study would not have been possible without their drive and commitment. I also acknowledge the support received from their employers who recognized the importance of their participation in this study.

This study is a collaboration with *Elder Abuse Ontario*, and particularly, a partnership with Josée Miljours, the Regional Consultant for the Northeastern Ontario region. Throughout this study, I have developed a new appreciation for Josée's efforts to ending OAM and her dedication to, and esteem for, her Northeastern networks.

This study is generously funded by the Ontario Trillium Foundation.

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Background

In Phase I of this study, the professional experience of encountering cases of mistreatment of an older adult with dementia was explored and a greater understanding of the socio-legal health care contexts within which cases are experienced was achieved. This phase revealed challenges common to all practitioners, regardless of their discipline and of their geographical region in Northeastern Ontario.
Throughout this study, the concept of professional agency, "an emergent, affective, and cognitive process that permits us to respond to our situations in meaningful ways" (Frie, 2011, p. 341), was also examined. In the current contexts, it is my conclusion that professional agency is rarely achievable in cases of OAM and dementia. Despite the best intentions and efforts of participants, responding to situations of mistreatment and dementia in a "meaningful way", was only possible in limited circumstances. Unfortunately, more often, experiences of alarm, crisis, worry, doubt, fear, frustrations and systemic pressures prevailed.

The primary goal of Phase II was to develop action plans to address some barriers in the present contexts. It is hoped that these actions projects will ultimately improve professional agency. Of great importance was having the voices of these practitioners heard as "when persons have no voices other than prevailing discourses in which they exist, not only is agency dismantled, the possibility of social, political, and psychological change is undermined" (p. 348).

The findings from Phase I of the study served as the background for this final Empowerment Phase. Participants received those findings in the Interim Report prior to coming together for these focus groups. To guide discussions in the Phase II focus groups, some primary findings from Phase I were presented in the following three categories: the experience, the socio-legal health care contexts, and professional practice.

"when persons have no voices other than prevailing discourses in which they exist, not only is agency dismantled, the possibility of social, political, and psychological change is undermined"

(Frie, 2011, p. 348)

1.1 The experience

Encountering OAM in the home was a revealing yet distressing intimate experience. Although access to the older adult in the home was a privilege as it permitted the gathering of valuable information pertaining to risks and control, it also created distress for these participants who were increasingly exposed versus those who did not access the home. This exposure created an imbalance between those confronted with the mistreatment versus those who were not privy to this information but yet were the ultimate decision makers.

Given the precarious nature of cases of OAM and dementia, practitioners feared increasing risk in the home after their departure. In some situations, where this risk/benefit calculation was perceived to be too great, practitioners erred on the side of caution; instead of intervening to end the mistreatment, most increased services in the home to provide more supervision. Openly declaring their concerns about mistreatment to the mistreating caregiver, without being able to protect the older adult, was considered a dangerous intervention.

Practitioners described visceral alarm reactions when confronted with situations of mistreatment. A swirl of emotional, cognitive, and physical reactions occurred. Despite this swirl, a professional armor was maintained while in the home. Disbelief was common as practitioners struggled with the reality of what they were witnessing. A process of realization followed, if the professional permitted this morally challenging acceptance. The challenge was then to transform these reactions into the facts required to work with

The experience

- **Revealing yet distressing**
- **Fear of increasing risk**
- **Emotional/cognitive/physical assault**
- **Professional armor**
- **Waiting for crisis**

Socio-legal health care contexts

- **Lack of adult protective legislation**
- **Inefficient current resources**
- **Social perceptions of aging and dementia**
- **Family issue versus societal problem**
- **Insufficient home care service**
- **Lack of caregiver support**
- **Compassionate fatigue**
- **Northern/rural challenges**

Professional practice

- **Peer support**
- **Lack of organizational P&Ps**
- **Losses to formal networks**
- **Lateral conflict**
- **Struggle-professional, legal, and moral duty**
- **Discouragement**
- **Hopelessness**

police, lawyers, and the current legislation. A vast gap exists between the familial home health context where cases are experienced and the legal system where cases are judged.

> Within the current contexts, waiting for a crisis to occur was frequently the only means of providing protection. As ending the mistreatment was not a controllable outcome within the home, the crisis, in the form of a medical occurrence requiring hospitalization, or a long-term care crisis application, was unfortunately the only way to get the older adult out of the home and in a safer environment where the proper care could be received. Practitioners described the distress associated with waiting for this crisis to occur and the ultimate relief of its occurrence.

1.2 Socio-legal health care contexts

> By far, the greatest challenge shared by participants, regardless of their discipline, was the lack of adult protective legislation in Ontario. They expressed bewilderment that policy makers did not understand the crucial need for legal support, the lack of application of the Criminal Code of Canada, and problems of requiring victim statement from the older adult in cases of dementia and charging their caregiver. Some expressed hopelessness in the present legal context which they described as being ageist as it failed to protect the rights of older adults as it aims to do with children, those with a developmental delay, and in cases of domestic abuse. Of particular importance to the home context was the ability of the mistreating caregiver to refuse access to the home, a frequent occurrence in which police have no power to intervene without proof of imminent risk.
>
> Many expressed frustrations with existing structures which are cited as resources in cases of mistreatment: the Ontario Public Guardian and Trustee and the Health Consent and Capacity Board. Few shared positive case outcomes. In general, a sense of apathy prevailed regarding the helpfulness of these structures.
>
> Social perceptions of aging and dementia were described as barriers to the acknowledgement of mistreatment of the older adult with dementia. Indicators of OAM were applied to examples of children illustrating the societal normalization and acceptance in cases of older adults but yet indignation when the victim was a child.
>
> The perception of OAM as a family issue versus a societal one was also deemed to be problematic as it kept the problem hidden only to be identified and addressed by the professional having access to that home. To also be considered when dealing with OAM and dementia within the home is the essential role played by the caregiver in keeping the older adult in their home. Given current service limits of home and community services, informal caregiving is pivotal to preventing long-term care placement.
>
> The home health and community supports contexts were also deemed unsupportive due to insufficient service provision in the home, the inability of current service allotments to meet the complex and high needs of the older adult with dementia/caregiver dyad, and the need for service planning with the caregiver who may indeed be perpetrating the mistreatment.
>
> Professional practice revealed that caregiver compassionate fatigue was certainly a risk factor for mistreatment in cases of dementia. Numerous cases were witnessed and the progression of the disease and responsive behaviors were of increased concern. Frustration was shared about the need but inability to provide increased supervision, services, and accompaniment in these cases.

"Most interesting is again the focus on compassion fatigue. I have seen some of the best grounded moral people fall to this risk factor. We need to recognize it and provide immediate support to the caregiver - this will provide immediate relief for the patient".

In the more northern and rural communities, participants voiced important geographical restraints of large districts to cover, distances to travel, and winter conditions which limited their ability to address some cases. As well, limited human resources contributed to the isolation of the older adult/caregiver dyad as well as the isolation of the professional who felt alone in confronting these cases. In these areas, home health care provision was limited as well as community resources such as adult day programs, an essential resource to decrease caregiver compassionate fatigue.

1.3 Professional practice

Primarily, support from their peers helped practitioners through these cases. For some, supervisory support was also available. These sources provided debriefing, support, and guidance. No participant was aware of organizational documents such as policy and procedures or decision trees to guide them. Some had developed informal networks within their communities of practitioners they knew they could rely on for support.

Where formal networks did exist, many members expressed discouragement, having served as members for decades, without seeing any positive changes. In fact, many expressed disillusionments with losses of prior gains such as senior liaison officer positions and funding for OAM community projects.

Unfortunately, within these informal interprofessional teams, lateral conflict was noted in many communities. Faced with complex and unsolvable cases, practitioners questioned each other's roles and responsibilities, sometimes holding unrealistic expectations of each other. Communication and team building, essential components to interprofessional team functioning, is a luxury in the present context of fiscal restraint and limited resources.

For most, uncertainty reigned between professional, legal, and moral duty. In the absence of professional guidelines and legislation, a moral struggle resulted. Values of respect, dignity, safety and protection prevailed. Whereas, in one's professional life, experience usually leads to competence, this does not occur with this phenomenon as there are no rules to follow, no process to learn, no framework to follow. In cases of OAM and dementia, more exposure to cases instead lead to more critical thinking, more failed attempts at utilizing the existing resources in the current contexts, more frustration and feelings of not meeting the needs of the at-risk older adults in their care. For some participants, dedicated to this issue for many years, discouragement and sometimes hopelessness was shared. Rule bending did occur as ethical decisions were made guided by principles of safety and risk. Participants longed for clear professional guidelines pertaining to what was expected of them and legislation to support them.

1.4 Critical Social Lens

In Phase II, participants were given a challenging task: to envision the opposite of the present status quo. This task was daunting at times as the current socio-legal health care context has presented obstacles for over two decades during which time some of the participating practitioners have channeled their efforts towards resolving this issue. However, practitioners were able to come together, push beyond the borders, and envision action plans, that, pieced together, will positively impact this phenomenon, professional practice, and the older adult/caregiver dyads in the domestic setting.

Phase II Design and Methods

2.1 Sampling

Participants from Phase I were invited to participate in focus groups for this last phase. Participants from both urban and rural communities came together in four Northeastern Ontario geographical districts for this study. The estimated size of the groups was of 9 participants.

Methods

Focus groups were chosen to replicate the dynamics of everyday life social interactions for these practitioners who, ideally, would come together to manage cases of OAM (Kamberelis & Dimitriadis, 2011). In order for all participants to have the opportunity to share their unique perspectives, writing of personal reflections was requested prior to group sharing. These individual reflections were then collected and reflected in these findings.

For each finding, participants were asked to reflect upon and write their:

a) thoughts and feelings (examine current beliefs, assumptions); what was most interesting, surprising, and concerning;

b) imagine, in a utopia, the opposite of this challenge (because we are limited by our current contexts) and their recommendations for this field;

c) reflections on possible actions to achieve this utopia; their thoughts on participation in the study, their hopes for the future in this field, and their recommendations for this field.

2.3 Analysis

In this report, a descriptive analysis of findings is provided. A more in-depth thematic analysis will be completed prior to publication of findings in the scientific literature analysis (Braun & Clarke, 2006; Tuckett, 2005).

3. Findings

3.1 Participants

Thirty-one practitioners participated in Phase II. Their backgrounds were varied: nursing, social work, gerontology, recreational therapy, psychology, physical education, business administration, criminology, and corrections. These practitioners represented both urban and rural communities coming together in 4 geographical districts.

3.2 Focus groups

Four 3-hour long focus groups were conducted, transcribed, and analyzed using NVivo11 software. Each participant's written personal reflections were added in the same fashion. Findings are organized into thoughts and feelings, the opposite situation in an ideal world, and possible actions to achieve these ideals. Supporting verbatim is offered, and interpretation is offered.

Thoughts and feelings about study findings.

After presenting findings from Phase I, participants were asked to reflect on the thoughts and feelings elicited.

Home and family sanctity.

Participants spoke about the isolation of mistreatment occurring within the home context: "... it's clear abuse happening in the home, isolated from the rest of the community". "It's disturbing, we're isolated already". "They're not seeing what I'm seeing. What you are witnessing on your own.

In addition to their isolation, practitioners also described the isolation of families of older adults with dementia, for many reasons. Firstly, past problematic family dynamics may lead to a caregiver/older adult relationship that should not occur: *"if you have a spouse or a child that was abused growing up, they're going to get that back if they end up being caregiver, put in that situation and not wanting to be in that situation".* (lit about being thrust into the role) (lit about retaliation)

Families developed their own internal coping mechanisms in response to the dementia. These mechanisms soon became ineffective: "*they tend to stay within the family so they don't really look to other people for help because it's, they think that they should be able to do it themselves, then things escalate"*. Families faced with dementia may remain in disbelief and not realize the progression of their fatigue: *"I think families aren't always aware of even what's going on because a lot of times they find themselves in this situation, it's not necessarily one that they envisioned, imagined and maybe they've never asked for help".* This speaks to the notion of caregiving as a breeding ground for mistreatment.

Thoughts and feelings about study findings.

- ✓ Home and family sanctity
- ✓ Emotional, cognitive, physical storm
- ✓ Do not feel trusted and validated
- ✓ Helplessness
- ✓ Hopelessness of contexts

In trying to accompany families in this journey, and attempt to prevent mistreatment, practitioners encountered challenges: *"we support many people in the early stages and we call them it's like no, no everything's great so after a year, if they haven't accepted any support and we haven't done anything, we'll discharge but we know down the road….Crisis will escalate….And that's exactly what happens, there's a crisis….it's really important to get in early and to have people understand the social and family issues that could arise with this illness….Because a lot of times, by the time someone refers to us, they're almost in crisis and we're not a crisis service so then (we are) trying to do dual*

duties of doing education with them and providing emotional support. They're not really ready to or not able to listen or learn anything new that would help them provide better care".

Inserting oneself into the sanctity of the home and family, was an unwanted but unavoidable occurrence. Practitioners wanted to help, but yet, interventions could not be standardized as the mistreatment was occurring within the family dynamics: *"every situation in a home where there's some tension that builds up has its own story".* This was an uncomfortable place to be with added challenges of not knowing all of the facts, of hidden secrets, of the human caring piece of dementia, and of only having pieces of the puzzle provided by a snapshot into the family's life.

When these families interacted with other components of the health care system, for example in the emergency or in-patient hospital units, similar concerns were shared as discharge back home was an eventuality: *"you know that there's something going on, you know the dynamics of the family, the makeup of the family environment where people are being cared for, just the dynamics. We're not sure of the acuity or the chronicity of a situation. So very often these situations are defaulted to me. The nurses are experiencing concern but we may still not be able to assist that person in hospital even though it's a safe environment. Discharge is still back to the home if that's what the person indicates they wish to do and even with dementia…(because) home is all they have".*

"I feel like I would not know what to do. I would definitely need to talk to someone and talk it over with someone in this situation I guess like I would probably want to take the person out with me, like if I felt that fearful for myself and for the person like I would not be comfortable leaving I don't think like. I don't know, I guess you'd really have to gauge what's going on".

"I'd probably be in a little of a panic. Who do I call? What do I do? Immediately write everything on my observations, conversation just to keep track of everything. I would feel stuck and confused and I would feel helpless. And I would also feel if I did something would it create a worse situation?"

"The terminology that you used professional armor was really interesting to me. I could certainly relate to that knowing you're in a house where your heart is beating and your hair is standing up on end, all of those things that we feel that you know, oh my goodness this is so not good, but I'm staying here ,and I probably shouldn't, and you're toying with, your head's going 20, 000 different directions, and you want to run, but you don't, and you can't, and you're not going to, and then you're calm, you elicit that whole piece, and then you leave, and you're shaken".

Emotional/cognitive/physical storm.

Findings from Phases I and II revealed the occurrence of an emotional/cognitive/physical storm within the professional. Examples of this storm are provided to the right.

"from a police standpoint, often times you have a gut feeling that something is not right but the law doesn't allow for gut feelings".

In response, many described maintaining stoic while in the home. This composure was referred to as 'professional armor'.

This experience was many things: uncomfortable, distressing, and unavoidable:

- *in our line of work, we're dealing with emotion most of the time. Because we are, we're just this bundle of I want to take you home and just take care of you there.*
- *I find it very sad because you know that the client, I put in quotations "suffering" it just sums it up*
- *you walk in and see a bruise on someone's face or do you walk in and hear someone say something a little harsher than you feel comfortable with. Like what is, like what are you feeling fearful for and everyone has a different perception of what fear looks like for them so I don't know.*
- *this lady that I had dealt with, the sadness that she felt when she actually realized her son was, she wasn't helping him, he was helping himself to her money and I think like dealing with all that emotion from her too and the upset and the crying and that's, I didn't feel prepared to deal with that.*

Practitioners fully experienced this 'storm' afterwards. At that point, worry might become the primary thought: *"if they're on their best behaviour with you there and that's the best they can do is that, what does it look like when you're not there? That would be my biggest flag and concern, you can't even reign yourself in when I'm here, what happens when I leave?"*

Do not feel trusted and validated.

The next challenge was to then translate this experience into the factual information. Participants spoke of the difficulty describing their concerns to those outside the home such as supervisors, police, and legal structures. "But a feeling that somebody's looking at you as if they're warning the mother don't you say a word or you know you're saying ok I saw a shifty look, it's a feeling I got between the two of them. Like I can see she was scared. How did you know she was scared?"

To address this difficulty, practitioners proposed that perhaps adopting legal language would be helpful to translate the message and be trusted in their assessment. *"In what words do police want us to tell them when we're reporting, what words do lawyers want us to say. Like what are, what words should we use that makes more sense to them…a piece missing that gives us credibility".* Police in focus groups reiterated that evidence was needed to permit them to intervene: "*from a police standpoint, often times you have a gut feeling that something is not right but the law doesn't allow for gut feelings".*

Participants also doubted their intuition, not trusting their assessment in the moment. Reflecting on past cases, practitioners realized they knew that mistreatment was occurring but had hesitated:

"those gut feelings do mean something … two situations that I can think of with caregivers where you just knew something wasn't right". "that's an instinct that we have that we know this, something is wrong and I think that we have to look at that and say okay, accept that as a real fact. That is a fact for us".

It is unclear why practitioners did not trust their judgement; some spoke of lack of expertise and not having skills, *"am I even qualified to assess these things? Do I have the proper knowledge level and/or tools to come up with those conclusions as well?"* Others referred to the difficulty accepting the reality that a family caregiver could mistreat the at-risk older adult in their care and the need to be right: *"you need someone that you can go to and say hey am I going nuts? Am I seeing this right?" … "if you're going to say that someone's doing something that they shouldn't be you better be right".*

"when you experience something at an emotional level, for me it's kind of the drive behind pushing forth and trying to problem solve or rectify the problem"

Some participants wanted to avoid the emotional reaction in an attempt to remain objective and not be judged as overreacting. They were apologetic for their response: "*unfortunately when we go on feelings … Oh, you're being emotional. They don't take it seriously and you're scared to cry wolf and then be portrayed as the emotional one that jumps the gun so you trust your own instinct but you can't, you need to be really careful getting it across because you don't want to come off like a crazy person, right?"*

"UNFORTUNATELY, WHEN WE GO ON FEELINGS … THEY DON'T TAKE IT SERIOUSLY AND YOU'RE SCARED TO CRY WOLF AND THEN BE PORTRAYED AS THE EMOTIONAL ONE THAT JUMPS THE GUN SO YOU TRUST YOUR OWN INSTINCT BUT YOU CAN'T, YOU NEED TO BE REALLY CAREFUL GETTING IT ACROSS BECAUSE YOU DON'T WANT TO COME OFF LIKE A CRAZY PERSON,

However, this emotional reaction appeared to not only helpful, it was essential as it served as the catalyst to being present, pursuing inquiry, thinking critically, remaining with, and intervening: "*when you experience something at an emotional level, for me it's kind of the drive behind pushing forth and trying to problem solve or rectify the problem…It is emotional and you do the ground work so by the time people that are in a position to do anything about it, like the Public*

Guardian and Trustee, they get all the facts but we've worked for months to get them those facts.

It appears that the emotional/physical/ cognitive storm permitted this working through; that this inner alarm, these inner screams should be embraced. Without it, practitioners might miss the occurrence of mistreatment. Frequently, concerns of mistreatment occurring within the home were not validated by others:

- "*we need to be validated and trusted and listened to when we're saying something*.

- ***powerless, out of control, sad and disappointed.***
- ***not empowered.***
- ***anger, helpless, want something done now not later***
- ***disturbing.***
- ***Distressed. They probably think who's going to listen to me anyways because they don't care.***
- ***then you run the risk of further like more things happening and people just being disenfranchised.***
- ***It's upsetting, you know the client's at-risk and your instinct is to protect them.***
- ***Distressed, that's what I saw, distress and angry because you know that it's going nowhere.***
- ***sometimes I don't want to know because I can't help***

- *when we have a feeling something that others find is unreasonable, like they don't want to listen, they've got you know, they've put up a block so no matter what you say or do it's not, it's not taken seriously enough*

Participants spoke of giving up when not being listened to: *"it can be disappointing for people who have that intuition and feel like okay, what do I do now. and then it can become disappointing so you might find that people start to report less and less if they don't find the responses that they feel are appropriate for what they're (seeing)".*

Helplessness.

The text box to the right demonstrates the strong feelings of helplessness experienced by participants and the resulting danger of looking away from the mistreatment. Within the present context, practitioners felt quite helpless.

This discouragement is further evidenced by statements after reading the Interim report:

"when I read your book (Interim report), and I was feeling oh my god, there's nothing we can do, like we might as well just, what are we going to do? Just turn our eyes away, it was awful. And even reading your book I felt that way, I felt reading everybody's scenarios and I felt so sad".

"I'm concerned to learn that the majority of practitioners did not feel that they had control in terms of the outcome of their case. I am not surprised by this, but certainly concerned".

Despite this feeling, practitioners persisted as they felt a moral duty to assist:

- *"I would be very apprehensive but I would continue to go".*
- *"Once I know, I'd have to act and I feel that it's our duty, we can't just turn our heads when we see it, we have to pursue. I wouldn't be able to live with myself if I knew that somebody was in an abusive situation that I knew about and I can't do anything about".*
- *"I feel it's our duty to each other and (our) human responsibility"*

Hopelessness of present contexts.

Numerous barriers contributed to a general feeling of hopelessness in the present contexts. This was palpable in all of the four focus groups. Participants shared their thoughts on historical, legislative, social, and health and community services factors that impede their ability to intervene in these cases.

Historical.

The field appears to be stagnant with little to no progress having occurred since the beginning of participants' involvement in this issue. Moreover, some important losses have eroded their hope for the future for older adult quality care, safety, and dementia care.

Some of these participants have been dedicated to OAM prevention and intervention for over 20 years. They shared how they first started, with many community stakeholders convening, and had high hopes. Progressively, and surely, these have been eroded; less stakeholders are dedicated for reasons that cannot be answered: *"We had some dynamic people at those tables …Everyone was represented".*

Those who remain involved share the frustration of stagnation and a feeling that those in power do not care about this issue. *"But that's what we've been doing at meetings since 1997 on this panel that started, (…) we are a fluff, …Things haven't changed at all in the last 20+ years… just the fact that the legislation has not changed in all those years…and a lot more has gotten more complicated". "We are too far behind in time to implement this. It should have been started 20 years ago and a proper action plan should be in place".*

Discouragement was strong: *"It just hit us like a ton of bricks that we've gotten nowhere and we're still nowhere". "Is there a solution? have we hit a brick wall?"*

Societal.

Participants were concerned with the absence of a strong governmental voice in this matter: "the government seems to think this is going to be done, this seniors crisis is going to be done after the baby boomers". Discussion pertaining to a recent member's bill for a National Seniors' Strategy provided some hope that OAM might be recognized.

Participants also voiced concern that society does not realize the importance of mistreatment by family caregivers: *"So many people working with older adults have the same view points and the overall public is so uneducated…. that 80 to 90% (of older adults) are victimized by their children".* Concern was shared about perceptions in the media that more *"acutely addresses abuse when it is physical or sexual abuse".* They were unsure about *"societal views/perceptions around "unseen" abuse such as social, emotional and/or psychological".* Equally, societal perceptions around dementia were problematic: *"people do not consider dementia as a social issue" …"so much stigma and taboo around dementia".*

Some practitioners described occasions where the caregiver's statement about the older adult's incapacity was accepted without questioning the older adult about possible mistreatment: *"we go away and we have no ability to talk with the individual and really figure out that you know what, she does know what she's talking about, and there is something bad happening to her… in all likelihood, I have to be honest, and it's sad for me to say, but in all likelihood that professional is going to go ok (and leave)".*

Lastly, the mistreatment of older adults with dementia was perceived to be an unacceptable yet tolerated phenomenon in current society. Participants whispered *"I hate to say it" … "I don't know, its' almost accepted".*

Legislative.

In the present legal context, practitioners must have an understanding of numerous pieces of complex legislation. Participants felt unsupportive due to numerous barriers which lead to hopelessness, disregard for the system, feeling disenfranchised, and wanting to turn away but, for those who participated, the latter was not an option.

- *"It seems that no matter where the person turns they're not protected".*
- *"I'm concerned to learn that although most front-line service practitioners are well intended and want to protect the wellbeing of the abused, that because of a lack in clear legislation, the abused older persons continue to survive/endure abusive environments".*

Decisions made by older adults' children who held a power of attorney were considered mistreatment in some cases, but practitioners felt very alone with this conclusion: *"people are more likely to keep the person at home and they're not really able to care for them well…sometimes the decisions around placement, where the person should not be living at home any more, but the power of attorney or the substitute decision maker isn't making that decision…your priorities are very much advocating that no this person needs to not be living at home and I mean it's neglect right, but then the steps we have to go through to make something happen don't always happen… it gets really complicated and …the other care practitioners in the circle of care feel like, again, we've done all we can".*

Participants explained specific examples of historical losses, becoming hopeful each time resources are offered, to then becoming discouraged once again once those resources fail to support them:

"The Health Care Consent Act came out in 96. We thought this was an opportunity for those situations, the mal intent or the neglect because it had been going on for a long time but there was no avenue before, so we saw it as an avenue … there were a few situations we presented to the Health Care Consent review board and thought we had tons of information that could support why there was that concern of neglect… there was no support from the legal system, you didn't have enough documentation, there was not enough this, that, so I mean it really and that's where we don't necessarily connect because what the legal system needs or wants is not necessarily what the health care system has because of confidentiality or different things. So that's where the gaps I found even after all those systems are in place it's still not helping". A fear of the legal structures prevailed: *"we don't, I'll be completely honest, want to go testify, we've had to do it…It's not something we want to do but if it helps...".* Participants hoped that structures such as PGT and ACE would become involved in creating *"the right infrastructure".*

Professionally, participants searched for guidance: *"I'm concerned to learn that there is still no legal responsibility from many professional colleges that necessitates reporting at-risk adults at risk as there is with children. As a professional for me there is always an obligation to provide follow through".*

Collaborative work between health, social services and police services was problematic. Positional power was sought, but, due to lack of legislative support, police could not help, which lead to an avoidance of the situation of mistreatment: *"if I was to call police or authority, will they be able to do something? and often, unfortunately, they can't, depending on the cases. Sometimes I don't want to know and my blinders go up to be honest because I know that nothing much is going to get done so I kind of try to avoid it".*

Police explained their limited ability to intervene based on the legislation. For example, one described that *"the threshold of reasonable grounds to gain entry into someone's home is set very high even for police".* If denied access to the home by a caregiver, they are unable to cross that barrier: *"we can do a well-being check but when we knock on the door, if no one answers the door, or if someone answers the door and goes ya, everything's fine here…. That's where it ends".* Police described further barriers when trying to pursue a case legally: *"and also going from there to the crown attorney's office, when the crown attorney reviews the case, they might decide that there's really nothing, these charges are not applicable and throw it all out…. So, everyone's hands are tied".*

In an attempt to circumvent these barriers, some participants described bending the rules, for example by sharing information of at risk older adults with colleagues. In their discussions around confidentiality, practitioners described divulging information when acting in the best interest of the older adult, but not necessarily due to imminent risk. Waiting for this severe risk placed practitioners, who are taught to prevent and care, in very distressing positions: *"you're seeing that they're just failing, they're losing weight, they're falling, they're… Like you're waiting for that crisis... She finally fell, broke her hip, ended up in hospital, went right to long-term care. But we had to have the crisis. We watched her silently suffer but nobody could be charged. She wasn't deemed incapable but she had dementia".*

Practitioners reported historical losses as new formal processes to protect confidentiality are perceived as barriers to protection. For example, some resorted to making anonymous reports to

the police as privacy legislation prevented them from sharing outside of the circle of care. However, police explained that anonymous reporting was problematic as it did not meet the requirement of threshold for entering someone's home.

Finally, the existing legislation and structures were deemed to be unsupportive: *"if we refer them to the consent and capacity board then ok how long is that going to take? We're in a crisis situation…It's always, it seems like it's always a runaround" …" but there's nothing practical coming out of it (referrals to resources), it's all our knowledge…the system is just broken and it's not us, we can't fix it".*

Health and community services.

In all communities, insufficient resources were described due to larger caseloads, fewer human resources, covering for unfilled vacancies, and large geographical coverage responsibilities: *"services are stretched*". This contributed to a lack of participation by some organizations to community networks for OAM, bringing some to conclude that this wasn't a priority for certain organizations. For those who continued to work together, there was a desperation around this issue: *"We have nowhere to go. We huddle together and decide ok, we call, and plea, ok this is what's happening".* Hopes of creating a community network for OAM was deemed unrealistic:

- *"I'm concerned to learn that not everyone is wanting to take responsibility for change - everyone has a role to play in taking responsibility".*
- *"There are few existing supports currently for responding to these situations".*
- *"The almost "pass the buck" attitude when it comes to the wellbeing and suspected mistreatment experienced by older adults with dementia".*
- *"We lack support … so many practitioners present to their jobs feeling unsupported".*

Service limits and provision were also considered insufficient to prevent and address mistreatment of older adults with dementia. The inability to provide adequate respite was a barrier discussed by most. This also caused some lateral conflict then organizations providing that service and others who felt they could do more. Frustration was shared of having to inform families that more care could not be provided. This was compounded by worry when families admitted they were concerned about their own coping abilities: *"I did have one son say to me before you know I don't know, I'm on the brink of…I feel like …I'm going to, something's going to happen, something bad is going to happen".*

Validation.

Despite all of these challenges, participants, by reading the Interim report and by sharing these thoughts and reactions, felt validated in their concerns and for many, no longer felt alone.

This validation permitted them to change the focus of discussion towards an attempt to envision a more promising future for OAM and dementia.

Ideals.

Participants were next asked to imagine an opposite world free from the challenges addressed in Thoughts and reactions.

Education.

In an ideal world…

- society would be sensitized to the reality that mistreatment can be perpetrated by a family caregiver towards an older adult with dementia. *"I think we not only need to get out there, we need to get people to feel it, we need to get people. It needs to become real…It needs to become a societal problem".*

- Every profession would receive minimum mandatory training on OAM (police, PSWs, front line workers, nurses, banks...)

- Training would be repeated regularly. In one community, training had occurred when the *Home Care Act* was enacted in 2000. A team of five was trained, but all of those left the organization shortly after. It is unknown if further training occurred.

- Practitioners want more than the standard list of indicators, risks, and types which they were all too familiar with. They sought more specific knowledge on pertaining legislation; what police, the HCC board and the PGT required as evidence of risk; and how to communicate this risk to their supervisors so as to speak a common evidence-based language; discussion about studies. Some did express apathy regarding current training opportunities which they had followed numerous times without it helping their practice: *"How many of these presentations have we attended? I've literally probably in my career I would say 20 different times...and you see, I still have no idea (what to do) half the time, no, 100% (of the time)".*

Empowerment.

To be empowered, participants, in an ideal world, wanted to:

- be free of the fear of increasing risk in the home setting and wished for caregivers to be open to their suggestions: *"in an ideal world, you'd feel comfortable to walk in and say this is what we have in place to help you do a better job here because obviously you're struggling and we want to help" …"you don't feel fear and the person's, you aren't worried about their wellbeing" ...."you'd be safe enough to do that"… "knowledge that your actions won't make it worse"…"knowledge about what to do next".*

- have their concerns validated
- have the ability to change situations immediately.
- have *"confidence in (their) skill level to investigate situations without accusing/assuming and having supports".*
- have realistic geographical coverage expectations

- have adequate support and resources

- in rural areas, have inclusion in other networks in bigger communities so they have a team that they could actually connect to

- have professional networks for debriefing, support

Infrastructure.

Participants wanted clarity, direction and support: *"clear code/guidelines/regulations of what to do similar to child abuse".* The developmental of *"Adult Protective Services to protect the well-being of at-risk adults with the purpose of educating, resourcing and repatriating families standardized (as per DSO/CAS legislation)"* was recommended by most participants.

Participants questioned the absence of legislation for at-risk older adults when it does exist for children: "*if a child was locked in a basement, and a senior was locked in a basement, which I experienced, is it because of the age that it's not looked at?" … "they become a senior they're just washed off the board you know"*

Borrowing components of the child protection infrastructure was discussed: *"Foster families for seniors…The idea is to be within your family and to be placed back in your family, for some that's a reality, for some it isn't and I think the same can be true for seniors you know. Not everybody is equipped to take care of a spouse or a parent".*

Participants proposed having dedicated OAM positions in every pertinent organization who, with the appropriate legislation, would have the authority to investigate suspicions, in the similar fashion that CAS does. This legislation would also support police in their enforcement role if access to the older adult in the home was challenged. Due to the high prevalence of mistreatment of older adults with dementia, the index of suspicion would be raised in cases of older adults with dementia: *"in dementia patients they would investigate all claims when it came to elder abuse"*. Police explained how they would like to have dedicated officers for older adults: *"we do have a youth bureau which are dedicated officers servicing youth situations, but we don't have the same for elderly people".* In another community, a participant mentioned recent training for domestic violence officers. Two participating communities did have such senior liaison officers but those positions were lost in recent years.

Lastly, participants proposed reflecting on the current societal/legal perceptions: *"A society where we recognize people with dementia that have limited or no capacity are at-risk and have a right to protection/protective services… It is a tough balancing act but our laws currently sway in the wrong direction".* When focusing solely on the right to autonomy, the right to protection from mistreatment appears to be neglected.

Inter-professional collaboration.

In an ideal world, discussions about OAM would occur openly within the team, which would include the family. Comprehensive care planning would serve to prevent crisis and would remove OAM from the secrecy that is the family sanctity. Ideally, the *"client would be supported and (we would not be) waiting for a crisis to happen".*

This team would include all organizations, not only those whose employees offer their time and efforts.

Interprofessional collaborations require communication and a mutual understanding of roles, responsibilities, and restrictions. In one community, an example of a positive collaboration was provided: *"because of that exposure that we had with the police, I have noticed in the last couple of years, often they'll call us if they've gone to a home, and they'll say we think maybe there's something going on here, like maybe some dementia… so getting us involved support wise so it's very slow, but it is a process, so I think building those relationships and having people*

understand your role, my role, how can we work together with these different kinds of rules and policies and support each other". This particular collaboration did end however; unfortunately, it appears that most collaborations are not sustainable.

In some communities, especially the smaller northern and rural ones, practitioners created their own informal networks: *"if there's anything we can do to start putting people in the home because reality is we're not going to get them out of that abusive situation right this second right? It's probably not going to happen….so if (professional) called and said hey (name) we think this is going on or this might be going on, is there any chance you can get the PSW's to be going in every morning to check to make sure she's ok?"* However, there appeared to be a gradient where this networking became impossible; smaller rural and more remote northern communities did not have the ability to create such informal networks as they were quite isolated in their community.

The sharing occurring within these small networks did raise issues of confidentiality as the older adult may not be in imminent danger as stated in privacy legislation. It was hoped that adult protective legislation would provide the legal support to share information when mistreatment was suspected.

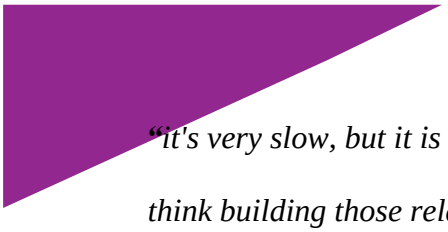
Systemic caregiver support.

Numerous cases were shared of fatigued caregivers, of the negative impact of dementia on the older adult/caregiver relationship, and of the risk of mistreatment within these dyads: *"I've been working with dementia people for 11 years now and I'll tell you caregiver stress is one of the biggest things where you'll get abuse"…."it's a priority, caregiver burnout or fatigue …those are the people we need to see quickly because if we don't get help for them, that's when they you don't know, they have no control over how they're going to react at times".*

Overwhelmingly, participants felt that caregivers were inadequately supported in their essential role within the current system: *"I would like to see the caregiver taken care of as much as the person needing care….so we're saying to 84 year old mom, that's your husband with Alzheimer's, good luck, we'll see you to bathe him twice a week for half an hour, 40 minutes, 20 minutes because I have to drive all the way there… so really they need more support before they get to that point and real support, not just we'll support the person with dementia. Let's talk about supporting that caregiver, what can we do to keep you healthy emotionally, mentally and physically?"*

Caregiver contributions were not recognized in the present health care system: *"The health system would collapse under its own weight because that's how valuable the caregiver is and yet they're not acknowledged as valuable".*

Participants suggested increased adult day programs, with funding to address the financial burden, and in all areas as it currently is not available in many rural areas forcing dyads to travel 1 hour or more to attend for the day.



"it's very slow, but it is a process, so I think building those relationships and having people understand your role, my role, how can we work together with these different kinds of rules and policies and support each other".

In addition to compassionate fatigue, the isolation experienced by these dyads due to the diagnosis is an important risk factor for mistreatment: *"this is the loneliness existence*

we've ever had since we were diagnosed because our friends left us. Our friends don't know how to deal with us, our family doesn't come around. ___ who used to pick up ___ every Monday for coffee doesn't want to do it alone anymore because he doesn't know what to say to ____. So that is all part of this, this is the caregiver now that is alone in this job because other people don't understand Alzheimer's".

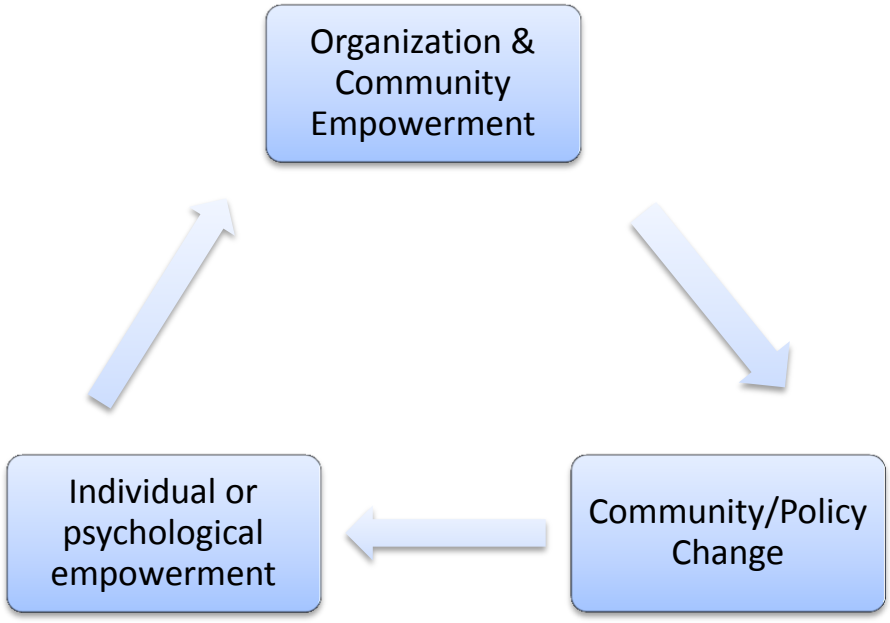
A lack of societal understanding of the magnitude of this caregiver burden was shared: *"society created this in the first place…there is that expectation that caregivers should be providing that 18 hours of care every day…that shouldn't even be…there should be more hours of caregiver support … there's a lot more that should be done".*

Concern was also shared about dementia care being absent from the Aging in place and Age friendly communities' initiatives. It is imperative that health practitioners become vocal in this respect: *"unless those people have an actual investment in knowing who lives in our community and what those people need then we're floundering, we can sit at as many tables as we like but unless you have community leaders informed and prepared to take action you know we we're still going to be sitting at committees ten years from now having the same conversation".*

Action projects.

After discussing the new reality needed to support practitioners with these cases, discussions aimed to identify action projects, within a realistic scope for the groups, that could address the ideal.

Contexts, empowerment and synergy.



Delp, Brown, & Domenzain (2005) Relationship between levels of empowerment and community/policy change (Reprinted with permission)

Within the four focus groups, many ideas were generated creating excitement in some groups, caution and doubt in others. It should be remembered that some of these participants have long been disappointed with the lack of progress and even losses in their fight against mistreatment. Participants voted on the idea best suited for their community, most likely to produce positive

change in this field, as well as for their professional practice, and most likely to increase the quality of care for the older adults and caregivers in their care. Five regional projects were agreed upon.

Create adult protective infrastructure.

In all four focus groups, regardless of the composition of the group and of the region, the focus of discussion ultimately became the need for an adult protective infrastructure. Therefore, although the first group decided to proceed with in a policy direction to influence legislation, all participants from the four regions will collaborate on this policy piece. It was deemed the most important action project that needed to result from this study.

How would infrastructure help?

Participants offered the following:

- ✓ "*acknowledge older adults' worth, their right to protection, their dignity"*
- ✓ *"address the current ageism of lack of protection for older adults"*
- ✓ *"just as child welfare and protection is more than a family issue, so too should be adult/senior welfare and protection"*
- ✓ Present laws speak to imminent and severe risk which minimizes interventions in the home context. As a result, practitioners spoke of waiting for a crisis to occur. This is quite different from the notion that any suspicion of mistreatment with children must be reported. Adult protective legislation could permit earlier intervention based on the presence of risk or concern, without imminence.
- ✓ presently, without legislation, the POA or SDM can block access to the home
- ✓ currently, some guidelines direct practitioners to contact police as a first intervention-discussions in the focus groups demonstrated how misguided this directive is; to enter a home where child abuse is suspected, police may accompany the CAS worker as her statement of risk is sufficient, based on the legislation, to enter the home-this is not the case if a professional is concerned for an older adult's safety-their concern does not provide sufficient evidence for entry
- ✓ present laws require a victim statement from the older adult which is highly unlikely in cases of dementia and problematic to seek from an older adult towards his family caregiver
- ✓ present rhetoric speaks to empowering older adults-not realistic in cases of dementia
- ✓ practitioners understand that the present system of HCCA, PGT, requires formal proof of incapacity; this is expensive and will not be done if the mistreating caregiver is POA
- ✓ privacy legislation is a current barrier to health/social/police sharing-does CAS legislation permit this sharing between health professional and police? would APS therefore allow such sharing? this barrier is problematic for all involved

One participant explained, very eloquently, how adult protective legislation is not about apprehension and removal: *"adult protective services can very easily mimic child protection services because it's not about apprehension and isolating that senior, it's about protecting the well-being of at-risk adults with the purpose of educating resources and repatriating families and very often with child protection services that is the outcome because families like anyone else, just because you're related doesn't make you an expert, whatever it is you're expected to do and my experience, although I've certainly seen some where it's been very intentional especially around financial abuse, but my experience is that if you provide people with some resources and education depending on how you approach that they are open … have someone assigned like you do with CAS, they're in the home, you can't say no, sorry you can't come in, they're authorized and they're allowed to go in under the law that protects that potential at-risk adult. We know that child protection services are not an ideal system. We've all read the stories and we all know based on our own work experience with child protection services it's not a perfect system. But I see that as being something that (adult protective services) is absolutely necessary, especially in view of the fact that all of those reports have come out with regards to the tsunami around dementia, we're seeing it, it's going to get worse, but not just necessarily for people with dementia, anybody that is at-risk as a result of their aging process and their experience with that".*

Next steps:

-complete background research on other Canadian provinces and countries which have adult protective services

-review Quebec's recent legislation for at-risk adults

-review Bill 148, private member's bill on mandatory reporting

-review the policy brief proposing a National Seniors' Strategy

-review existing legislation position papers: ACE, Law Commission of Ontario

-prepare a policy brief outlining the justification and proposing content for at-risk older adult protective services

-forward to research participants for their feedback

-make modifications as recommended by participants

-forward policy brief to a national target-possibly the *Standing Committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities* in support of the National Seniors' Strategy by September 30, 2017-see https://www.sudbury.com/local-news/now-that-the-house-has-backed-serres-senior-strategy-the-real-work-begins-637091

-participants may also wish to forward the policy brief to municipal or provincial government (Bill 148, the *Protection of At-risk Seniors in the Community Act, 2015*, introduced by member Soo Wong, of Scarborough–Agincourt -currently with Standing Committee on Social Policy. (Legislative Assembly of Ontario, 2015). (see details in Appendix A of the Interim report)

Caregiver support services.

Based on their experiential expertise, study participants clearly identified compassionate fatigue as a risk factor for OAM.

Caregiver stress has not been formally recognized in the literature as being a risk factor. It is therefore imperative that this finding be disseminated and acknowledged.

Participants described many cases of caregiver exhaustion, and their inability to address this adequately within the confines of the present health and community services. Current home care service plans are based on the patient's requirements for activities of daily living, not the caregiver's needs. Participants want to address this gap.

What would this look like?

This focus group was adamant that an action around formal caregiver support services was required although the conceptual clarity of this action needs to be determined. Further research will be required to reach a planning phase.

Participants were encouraged to brainstorm and to not rule out any ideas at this time.

Ideas included:

- determining a niche to prevent overlap of existing services;
- proposing a pilot project for a caregiver support program with goal of preventing mistreatment and crisis;
- preparing a grant proposal to fund the pilot project;
- in home respite;

Formally recognize caregiver

"they (patient and caregiver) should really be recognized as equally, and in the present system they're not, … the service allotments are based on the person's

- compassionate fatigue classes;
- education on risk of OAM;
- providing care for caregivers (art therapy, activities);
- include extended family support (for example grandchildren);
- partnering with Alzheimer Society on existing caregiver support modules.

Next steps:

- prepare background paper-why caregiver support is essential to prevent mistreatment
- research: how do other countries support their informal caregivers?
- what services are currently offered in Ontario? In Northeastern Ontario? (Adult day programs not necessarily available in smaller communities)
- forward background to participants
- plan proposed action
- prepare grant proposal

iii. Create community consultation table.

This group decided to develop an action that would address professional practice and intervention in their community: a community consultation table. Two primary reasons fueled this decision: the importance of support and consultation with these complex cases within one's team and within the social-legal-health care contexts.

Why?

Firstly, all participants spoke of their organizational teams, when these organizations were large

"The health system would collapse under its own weight because that's how valuable the caregiver is and yet they're not acknowledged as valuable".

enough, as their primary source of support. They sought from them debriefing, consultation, and guidance. What wasn't explicit, but could be inferred from this study, was that not sharing with others, and thereby remaining isolated with the burden of these cases, may cause moral distress and is not conducive to intervention. Also, although speculation, given that these study participants, who volunteered as this topic is of interest to them, described numerous cases of OAM and dementia, there is a possibility that many more practitioners struggle with these cases but have not come forth. Indeed, these practitioners may be even more perplexed with these cases than those in the study. A consultation table would therefore offer support to all practitioners regardless of their level of exposure to these cases.

Secondly, during focus groups, participants shared frustration about not having the answers with specific expertise such as legislation, roles, financial institutions, mental health care, home care, to name but a few. Currently, practice in some communities was to informally reach out to colleagues in other sectors with whom practitioners had positive working relationships from past cases. Some practitioners did not have this resource and felt very alone and unsure on how to proceed in cases. A consultation table would provide that ability to tap into valuable expertise outside of one's team.

How and next steps?

The principle of interprofessional teamwork is appealing to all. Within their own organizations, practitioners described positive outcomes from teamwork in various forms: situation tables, weekly huddles, and risk management meetings. However, there are challenges and sustainability may not be possible. In this particular community, a case review team was initiated but did not last. As well, in most participating regions of this study, elder abuse teams had ceased serving this function.

While it is exciting to imagine a positive resource for these practitioners and their community, reflection on failed attempts is essential as these occurrences are discouraging. Reasons offered for lack of sustainability and required next steps therefore include:

Challenge of confidentiality: *"we weren't breaking confidentiality though but everybody knew what everybody was doing"*. This was echoed within other small communities. A tool that might be useful was offered by one participant in Phase II: *"Guidance on Information Sharing in Multi-Sectoral Risk Intervention Models"*. This guide is available on the memory stick attached to this report. It proposes a filter approach to sharing information in at risk situations.

Human resource challenges and rising caseloads preventing members from consistent participations:

- *"I just don't think it's attainable or sustainable…I feel bad saying that but with everybody especially up here in this area and the caseloads and the work that we have I don't think it, in my opinion, I don't know if you disagree but to get us all at the same time, same place".*

Discussion around other forms of consultation teams revealed that some communities have been able to maintain their teams. A review of existing teams throughout Ontario and in other provinces without adult protective legislation is required to highlight conditions for success and how to overcome challenges.

Expertise is essential. Practitioners verbalized frustration about specific gaps of knowledge such as legislation, police intervention, capacity. Without this expertise at the table, debriefing and

support are possible but not consultation and going forward: *"There would have to be somebody that is an expert at capacity or knows the capacity board. There would have to be somebody that knows the justice system. There would have to be that one key person that knows it in and out that you know we can pull from and say listen…these players need to be here and this is what's going to happen and that's how I would see it working" …. "lawyer, doctor, police…I know that these people would show up (in this community)"*

Participation by all pertinent stakeholders. Practitioners, in all regions, voiced concern that some organizations are never represented at current meetings. This was also a source of lateral conflict. This concern would require buy-in from all administrations with a dedicated individual representing each organization with protected time to assist and serve.

Formal organization. Participants in all communities shared the challenge of contributing to projects on OAM due to their full-time employment obligations. Having a funded position to strictly coordinate/lead this table was viewed as a driver for success. Such time-limited funding has been obtained in other communities (ex: Peterborough). A grant proposal would be required if the group wished to proceed with that request.

Information sharing to community-Once the consultation table was in place, dissemination of its existence would be offered to organizations within the community. A tracking mechanism (while maintaining confidentiality), would be essential to tracking the success of the initiative.

Scope of project: in some smaller communities, practitioners might be very isolated and expertise might be absent; would this consultation team be regional (for the NorthEast) or local? Could case review be conducted via teleconference? Via email?

In this community, other positive changes provided hope that the group could build on the momentum of current successes: *for (region), we are kicking it up a notch with our family health teams, with our BSO, with our support, our adult day program, our nursing homes, the geriatric clinic that's just opened, it's an amazing service for this community like, we're doing well.*

Influence policy makers.

This community chose an action to influence their local decision makers. An excellent way to preface this action is to share with you decisions previously made about this study: the topic, the theoretical lens through which to view the problem to be studied, and the two phase design of the study.

Why this topic, theoretical lens and design?

A reflection on the rhetoric of many documents on OAM reveals a troubling paradox: those who face cases of OAM have the greatest responsibility but yet hold the least power to effectuate change. Practitioners are told that they "should, ought to, must" intervene in cases of mistreatment, but yet are then abandoned with regard to intervention. Many participant quotes can be found in both this report and the Interim report to illustrate this conclusion.

It is for these reasons that this study was based on a critical social theory lens exposing insights into the socio-legal healthcare context within which professional OAM practice is embedded. This theory explains that we are all "social agents" (with) progressive tendencies…interests, purposes, or needs that cannot be satisfied within the context of the present social order...that they do not control… (and who) are willing to put the research findings into practice" (Comstock, 1982, p. 379). In other words, practitioners are currently forced to work within the confines of present contexts which do not support them in their professional practice with OAM and dementia.

Therefore, the action, the third phase of this study, decided upon by this focus group, to present before local council in order to impress upon them the need to address dementia and OAM requires that we act as "social agents" or become "political animals" as offered by one participant.

"Well we become political, we need to become political animals, we can't be afraid to do that… unless you have community leaders informed and prepared to take action, we we're still going to be sitting at committees ten years from now having the same conversation".

Next steps

Review the Dementia strategy

Review the literature on Friendly Aging communities

Look to literature for other successful models

Meet with focus group to outline presentation

Present to local council

Possibly offer content of presentation to other communities wishing to impress importance of dementia and OAM upon their local leaders

Use of evidence-based tools inter-organization.

In the two phases of the study, when asked, participants were not aware of any organizational policy/procedures or tools to use for assistance with cases of OAM. Yet, evidence-based tools can be used for screening, identification and to guide some aspects of intervention. Participants in this group decided to pursue the use of evidence-based tools in their practice, to be adopted within their organization, and to serve as communication tools between organizations. These objective tools, it is envisioned, will:

Offer language for credibility: participants were challenged to translate their intuitive thoughts and observations into the objective factual information required by those making decisions (ie: supervisors, police, lawyers, resources such as PGT). Adopting an evidence-based tool could assist with this 'translation' *"having some concrete tools that are universal, everybody's using the same language, everyone's using the same tool, so it's more concrete".*

Be empowering as it will provide confidence: *"Empowering for me like the fearful part, it I think, like going back to what we talked about earlier with knowing the legal jargon so what do I need to feel empowered as a worker going into the situation so I'm not completely overwhelmed and like fearful of what might happen to me or what might. Like what do I need to empower myself?"*

Know what is data is required: "we need to know what they need at the end so that when we're doing our part we're screening appropriately". "*we can put it in our charts, we can type it up so if anything gets subpoenaed, it says right in our notes, we documented words that made sense in the court room".*

Requires a process within organizations for tool to serve as communication of risk: *"in our agency a PSW wouldn't start calling family or start calling police or whatever, they go to their coordinator who is a nurse, who has some skills, knowledge and judgment level and where to take it and how to deal with it"*

Next steps

- ✓ some paper pocket tools will be distributed to participants-those have been validated and are useful
- ✓ some other tools will be loaded on memory stick
- ✓ review all existing tools in the academic and grey literature to offer to group
- ✓ discuss adoption of tools (individual, organizational)

Conclusion

"we need to become political animals,

we can't be afraid to do that"

Professional voices

In this field, practitioners are frequently asked to empower the older adults in their care. In discussing empowerment, Chavasse (1992) stated that practitioners "cannot empower others...until they are empowered themselves" (p. 532). Reflections from participants offer some hope and courage to persist:

- I think what's important for all of us around this table is to recognize that we can't stop even though we feel that our hands are tied in several cases that we've worked with, we can't stop trying to make things better and do things and I think that this process, this study, these conversations have to keep happening in order to do that
- But today I feel like maybe we're going somewhere. We're finally getting out of that just, we recognize it. I'm sick of being told, I can tell you verbatim everything about abuse. I could tell you the sexual abuse, emotional, all that stuff but ask me what to do about it and I go. I don't know what the hell you do about it, I just know it exists so if out of yours comes action.
- I was reading it because I thought all these people are saying what I've been through….All these years….Yes, yes…Because it's never really been down on paper in such a reality … what was nice about it, it was that you're reading all these things that you've already been through and felt helpless….and other people are feeling the same way….yes, yes... it is something that hopefully we can...bring action.
- We obtain a "voice" in affecting change to improve quality of life for persons identified in study.
- Given the expertise and experience in the community, practitioners are being heard.
- Our excitement that we are moving forward as a group to try to change things/reduce elder abuse.
- More of this, a larger group voice!

Next steps

Our work together is far from over and in some ways, is just beginning.

There is much work to do on these 5 exciting projects which will all contribute to improving professional practice, communities, policy, and the care received by older adults and their caregivers.

As we progress, I will keep you informed via email.

Please do the same keeping me informed of your thoughts,

Again, I applaud you for your efforts, time, and tireless dedication.

Warm regards,

Jeannette

By permitting practice to inform research and policy, the field of OAM and dementia can progress.

Appendix P-Laurentian University Research Ethics Board Approval

APPROVAL FOR CONDUCTING RESEARCH INVOLVING HUMAN SUBJECTS
Research Ethics Board – Laurentian University

This letter confirms that the research project identified below has successfully passed the ethics review by the Laurentian University Research Ethics Board (REB). Your ethics approval date, other milestone dates, and any special conditions for your project are indicated below.

TYPE OF APPROVAL / New X / Modifications to project / Time extension

Name of Principal Investigator and school/department	Jeannette Lindenbach, PHD in Rural & Northern Health, supervisor, Kristen Jacklin NOSM
Title of Project	OAM, dementia, and the family caregiver in the rural Northeastern Ontario home: The influence of context on professional agency
REB file number	2016-05-14
Date of original approval of project	July 20, 2016
Date of approval of project modifications or extension *(if applicable)*	
Final/Interim report due on: *(You may request an extension)*	
Conditions placed on project	

During the course of your research, no deviations from, or changes to, the protocol, recruitment or consent forms may be initiated without prior written approval from the REB. If you wish to modify

your research project, please refer to the Research Ethics website to complete the appropriate REB form.

All projects must submit a report to REB at least once per year. If involvement with human participants continues for longer than one year (e.g. you have not completed the objectives of the study and have not yet terminated contact with the participants, except for feedback of final results to participants), you must request an extension using the appropriate LU REB form. In all cases, please ensure that your research complies with Tri-Council Policy Statement (TCPS). Also please quote your REB file number on all future correspondence with the REB office.

Congratulations and best wishes in conducting your research.

Rosanna Langer, PHD, Chair, *Laurentian University Research Ethics Board*

Appendix Q-HSN Research Ethics Board

Health Sciences North
Horizon Santé-Nord

Research Ethics Office
Northeast Cancer Centre, 1st Floor
Room 12035
41 Ramsey Lake Road
Sudbury, ON P3E 5J1
t: 705.523.7100, ext. 2409
email: reb@hnsudbury.ca

To: Dr. Kristen Jacklin (Student: Jeanette Lindebach)

Study Title: **Older adult mistreatment, dementia, and the natural caregiver in the rural Northeastern Ontario home: The influence of context on professional agency**

Sponsor/Funding Agency: Ontario Trillium Foundation

REB Review Type: Delegated

Date of Meeting/Review: July 15 2016

Expiry Date: July 15 2017

Notification of REB FINAL Approval

Documents Approved:

1. REB Application (received July 6, 2016)
2. Proposal (vs. June 8, 2016)
   - Appendix A- Organizational Information Letter
   - Appendix B NE CCAC Alzheimer's, EAO
   - Appendix C- NE Ontario Map
   - Appendix D- Information Letter for Participants
   - Appendix E- Demographic Information
   - Appendix F- Consent Form for Interviews
   - Appendix G- Interview Guide
   - Appendix H- Reflective Journal Guide
   - Appendix I- Consent Form for Focus Groups-Inquiry
   - Appendix J- Focus Group Inquiry Guide
   - Appendix K- Consent Form for Focus Groups Action
   - Appendix L- Focus Group-Action Guide
   - Appendix M- Timeline
   - Appendix N- Proposed Budget

Documents Acknowledged:

1. Letters of Support-Alzheimer Sudbury, Alzheimer Timmins, EAO, NE CCAC
2. Ontario Trillium Foundation Contract
3. TCPS-2 Certificate

Project Number: 16-041

This Project Number has been assigned to your project. Please use this number on all future correspondence.

Appendix R-Existing Pertinent Legislation

"Under the current regime, any person, including health care providers, *may* report suspected cases of abuse or neglect; however, reporting is not mandated except where the older adult is a resident of a Long-Term Care Home (LTCH) or a tenant in a retirement home. In addition, health care providers must report any suspected sexual abuse by another health care provider, no matter the setting. Should any person suspect abuse of an older adult, they may contact the police if the senior is capable, and either the police or the Office of the Public Guardian and Trustee (OPGT), if the senior is, or is suspected of being, incapable" (Advocacy Centre for the Elderly, [ACE], 2016, p. 5).

Under the current regime, if an adult with mental capacity gives consent to share information with another person or agency, there is no violation of privacy rights. When capacity is lacking, the health professional must consider criminal laws, capacity, substitute decision law, privacy, professional regulatory bodies, and the context within which the mistreatment is occurring.

6. *Criminal Code of Canada*- there are many forms of elder abuse that constitute crimes under the *Criminal Code*. "These include assault, assault with a weapon or causing bodily harm, sexual assault, forcible confinement, breach of duty to provide necessaries of life, uttering threats, intimidation, theft, theft by a person holding a power of attorney, fraud, extortion, stopping mail with intent or forgery. These crimes can be reported to the police but a police report is not mandatory" (ACE, 2016, p. 11-12).
7. *Substitute Decisions Act of 1992*- a healthcare provider who believes that a substitute decision-maker did not act in accordance with the person's expressed wishes or in the incapable person's best interests can apply to the Consent and Capacity Board (Wahl, 2012). "The Office of the Public Guardian and Trustee [OPGT] has a duty to investigate any such allegations, but again, the law stipulates that the person must be at the risk of suffering serious illness or injury, or a deprivation of liberty or personal security" (Wahl, 2012). The healthcare provider must provide evidence that the victim is incapable of managing his property or personal care; evidence that serious adverse effects are occurring or may occur as a result. To disclose without consent, "the custodian must believe on reasonable grounds that the disclosure is necessary for the purpose of eliminating or reducing a significant risk of serious bodily harm to a person" (Wahl, 2012).

8. The *Personal Health Information Protection Act of 2004 [PHIPA]*, can be helpful in that it gives health information custodians (HICs) broader power to use and disclose a patient's personal health information (PHI) without consent. Therefore, PHIPA actually broadens the ability to report abuse (Solomon, 2009). Specifically, "Disclosure without patient consent, specifically in regards to OAM, can be done: To eliminate or reduce a significant risk of serious bodily harm to a person (s. 40(1)); To the Public Guardian and Trustee (s.43(1)(e)); To a person carrying out an inspection or investigation under a warrant, or provincial or federal law" (s.43(1)(g)) (Canadian Centre for Elder Law, 2011).

9. The *Regulated Health Professions Act* (s. 36(1)(i)) "permits disclosure without consent for reasons that parallel the exceptions under personal information legislation, including

to aid a police investigation, where required by another law, or: If there are reasonable grounds to believe that the disclosure is necessary for the purpose of eliminating or reducing a significant risk of serious bodily harm to a person or group of persons" (Canadian Centre for Elder Law, 2011).

10. Context: There is currently no law in Ontario enforcing the mandatory reporting of mistreatment other than the following acts: *Child and Family Services Act, Long Term Care Homes Act, Retirement Homes Act, Coroner's Act, Highway Traffic Act, Regulated Professions Act* (Solomon, 2009; Wahl, 2012).

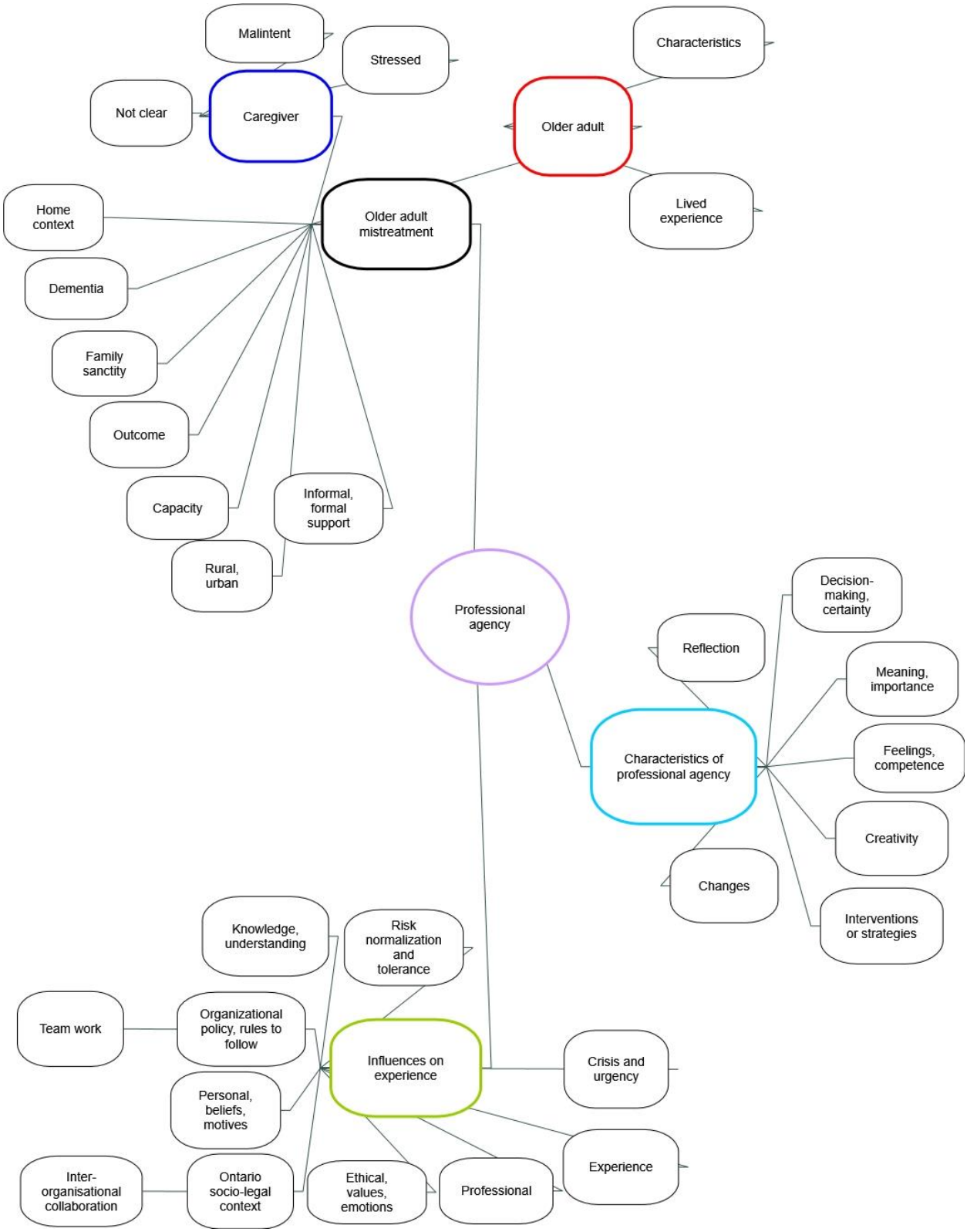
Appendix S-Existing Resources

Elder Abuse Ontario
Stop Abuse - Restore Respect

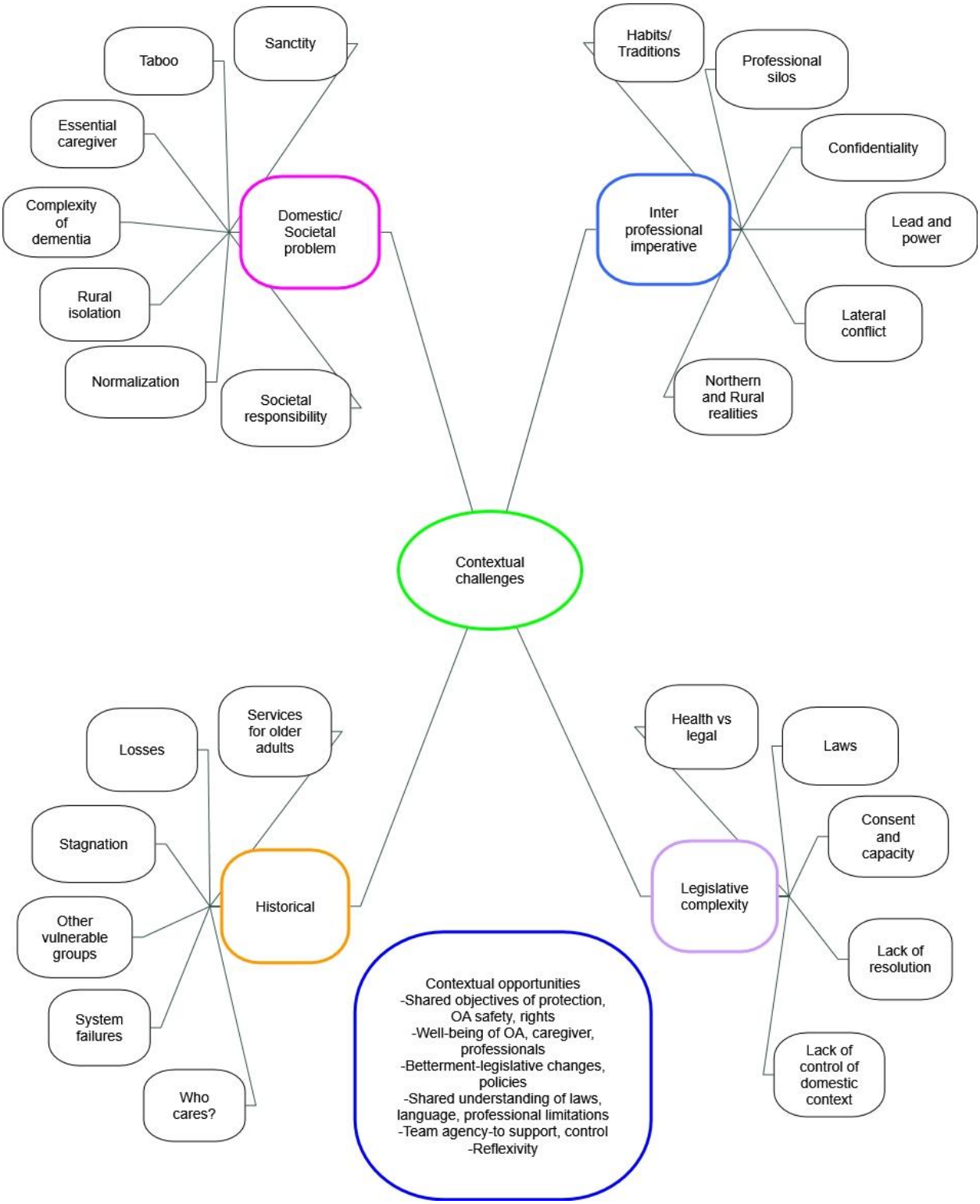
AGENCIES THAT CAN HELP

- **FOR EMERGENCIES 911**
- **ONTARIO PROVINCIAL POLICE 1-888-310-1122**
- **ONTARIO CRIME STOPPERS 1-800-222-TIPS (8477)**
- **ELDER ABUSE ONTARIO (EAO) NORTHEAST REGION 705-525-0077, HEAD OFFICE 416-916-6728 WWW.ELDERABUSEONTARIO.COM**
  Mandate: "To create an Ontario that is free from abuse for all seniors, through awareness, education, training, collaboration, service coordination and advocacy."
- **SENIORS' SAFETY LINE 211 OR 1-866-299-1011 (24 HOURS A DAY - 7 DAYS A WEEK)**
- **CANADIAN ANTI-FRAUD CENTRE (PHONEBUSTERS) 1-888-495-8501**
- **ONTARIO SENIORS' SECRETARIAT SENIORS' INFO LINE 1-888-910-1999**
- **ADVOCACY CENTRE FOR THE ELDERLY (ACE) 1-855-598-2656**
  WWW.ADVOCACYCENTREELDERLY.ORG
- **LONG TERM CARE ACTION LINE 1-866-434-0144**
- **RETIREMENT HOME REGULATORY AUTHORITY (RHRA) 1-855-275-7472**
- **OFFICE OF THE PUBLIC GUARDIAN AND TRUSTEE 1-800-366-0335**
- **VICTIM SERVICES**
- **NORTH EAST COMMUNITY CARE ACCESS CENTRE Call 310-CCAC (310-2222)**
- **LEGAL AID ONTARIO 1-800-668-8258**
- **CONSUMER PROTECTION BRANCH 1-800-889-9768**
  The Consumer Protection Branch is here to help you understand Ontario's consumer protection legislation and direct you to the right information. We mediate disputes between consumers and businesses, inspect businesses to help them comply with consumer law, and investigate or prosecute when it appears that consumer laws have been violated.
- **ONTARIO SECURITIES COMMISSION 1-877-785-1555**
  www.osc.gov.on.ca The Ontario Securities Commission administers and enforces securities law in the province of Ontario. Our mandate is to provide protection to investors from unfair, improper and fraudulent practices, and foster fair and efficient capital markets and confidence in capital markets.

Appendix T-Coding Framework-The Experience



Appendix U-Coding Framework-Contextual Influences



Appendix V-Coding Framework-Need for Empowerment